PREVALENCE OF EPILEPSY AND DETERMINANTS OF TREATMENT GAP IN PEOPLE WITH EPILEPSY IN RURAL LUDHIANA

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I hereby declare that the thesis entitled “Prevalence of epilepsy and determinants of treatment gap in people with epilepsy in rural Ludhiana” submitted towards partial fulfilment of the requirements for the award of MD in Community Medicine degree to BFUHS is a compilation of original work carried out by me under the supervision of Dr. Anurag Chaudhary, Professor & Head, Department of Community Medicine and Dr. Sangeeta Girdhar, Professor, Department of Community Medicine and Dr. Gagandeep Singh, Professor & Head, Department of Neurology. No part of this thesis has formed the basis for the award of any degree previously.

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Dedicated

to

my Teachers

&

Family

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It is the supreme art of the teacher to awaken joy in creative expression and knowledge.

-Albert Einstein

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Dr Aman Bansal

ABBREVIATIONS

AED	Anti-Epileptic Drug
BMI	Body Mass Index
DALY	Disability Adjusted Life Years
ETG	Epilepsy Treatment Gap
GCAE	Global Campaign Against Epilepsy
IBE	International Bureau for Epilepsy
ILAE	International League Against Epilepsy
NMHS	National Mental Health Survey
PWE	People with Epilepsy
RHTC	Rural Health and Training Centre
WHR	Waist-Hip Ratio
WHO	World Health Organization

ABSTRACT

Introduction: Epilepsy is a public health problem. It affects about 50 million people worldwide and causes a significant burden on 500 million family members, caregivers, and healthcare system. Despite the availability of effective antiepileptic drugs (AEDs), there is an enormous primary and secondary treatment gap.

Aim of study: To find the prevalence of epilepsy and study the determinants of the treatment gap in people with epilepsy in rural Ludhiana.

Materials and methods-The present study was a community-based cross-sectional study. It was carried out in the field practice area of Rural Health and Training Centre (RHTC) located at Village Pohir, Block Dhelon, District Ludhiana. The total population of field practice area (31043) was screened with Placencia's 9 item screening questionnaire by door-to-door visit. The screened positive individuals (n=195) were asked to report to RHTC Pohir. The neurology team clinically examined and/or diagnostically evaluated 187 individuals. A detailed study was carried out in subjects with active epilepsy (n=61) to study determinants of treatment gap by home visits.

Results: The mean age of the study population was 54.5 ± 13.4 years. There were 53.0% males and 47.0% females. The lifetime prevalence of epilepsy (n=78) was 2.5 per 1000 population, and the prevalence of active epilepsy (n=61) was 1.96 per 1000 population. The primary (diagnostic) and secondary (therapeutic) treatment gap were 3.3% and 45.9%, respectively. The lower socio-economic status, type of treatment sought after first seizure and treatment compliance counselling were among the various determinants significantly associated with the treatment gap.

Conclusion: People with epilepsy should be provided comprehensive health care services along with rehabilitation and employment opportunities. There is a need for awareness generation regarding epilepsy, its causes, and management modalities available to contain the treatment gap. In light of the paucity of neurology services, primary health care physicians can be trained to recognize the needs of PWE and outreach camps in public-private partnership can be organized.

Keywords: Epilepsy, Prevalence, Treatment Gap, Rural

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INTRODUCTION

Epilepsy was first mentioned by the Greeks as “Epilepsia” which means ‘to seize’. One of oldest account of epilepsy is found on a Babylonian tablet from 2000 B.C.[1] In *Corpus Hippocraticum* from 400 B.C., Hippocrates didn’t believe that epilepsy is a sacred disease which was in contrast to previously held beliefs of it being due to mystical causes. *Charak Samhita* gives a detailed description of epilepsy as “*aphasmara*” to be treated as physical disease and is known as “*mirgi*” in Hindi. Aphasmara is made of two words ‘apa’ and ‘smara’ where ‘apa’ means ‘loss of’ and ‘smara’ means ‘of consciousness or memory’.[2] John Hughlings Jackson, a British neurologist, described epilepsy as a brain disorder for the first time in the year 1873.[3]

The operational clinical and practical definition of epilepsy was recommended in 2013 by task force of International League Against Epilepsy (ILAE). It describes epilepsy as a brain disease defined by at least two unprovoked seizures which occurs >24 hours apart or one unprovoked seizure along with the probability of further seizures like the general recurrence risk of a minimum 60.0% after two unprovoked seizures over the next 10 years or if an epilepsy syndrome could be diagnosed. ILAE also defined Epilepsy as resolved for individuals who were seizure-free for the last 10 years, with no seizure medicines for the last 5 years or individuals diagnosed with epilepsy syndrome are now past the age for those syndromes.[4]

Global Burden of Mental, Neurological and Substance use conditions

Globally mental, neurological and substance use (MNS) conditions impose an enormous public health problem. They lead to premature mortality and affects the quality of life. MNS conditions includes depression, psychoses, epilepsy, dementia, disorders due to substance abuse and many other conditions. These represent approximately 14.0% of the global burden of disease (GBD). They

form 30.0% of disease burden imposed by non-communicable diseases.[5]

Non-communicable disease

India is passing through a phase of epidemiological transition as well as demographic and economic transition. The demographic transition will result in significant increase in manpower. India will be able to reap benefits from this transition only if workforce is healthy. India is facing a triple burden of disease i.e., communicable diseases, non-communicable diseases, and newer emerging pathogens. It is reported that about 60.0% of total deaths are due to NCDs. Among NCDs neurological conditions are on a rising trend by contributing 2.1% of total deaths occurred.[6]

Neurological disease

The increase in prevalence of neurological diseases is mostly due to lifestyle changes but can be consequent to rising life expectancy, industrialization or due to the improvement of health care services in preventive and curative domains.[6] The proportion of non-communicable neurological conditions and injury-related neurological conditions to DALYs in India increased from 4.0% to 8.0% and 0.2% to 0.6%, respectively from 1990 to 2019. However, in the same period proportion of communicable neurological conditions to total DALY's in India decreased from 4.1% to 1.1%. The top three contributors to DALY due to neurological disorders in India are stroke, headache disorder and epilepsy.[7]

Epilepsy

Epilepsy is one of the most common neurological diseases. It accounts for more than 0.5% of the GBD. There were 126,055 epilepsy-related deaths in the year 2016. Worldwide there are 39 – 54 million individuals suffering from active epilepsy. About 500 million people including family and caregivers of PWE are estimated to be indirectly affected by the disease. Approximately half of these individuals have active idiopathic epilepsy and other half have active secondary epilepsy. Prevalence of epilepsy increases with age. There

is bimodal age distribution with peaks at ages 5–9 years and at more than 80 years in developed countries and in developing countries peak is seen in childhood and early adulthood.[8] The occurrence of two modes suggests etiological heterogenicity. Prevalence is similar in men and women.[9]

Prevalence and Incidence

In 2016, Epilepsy contributed 11 to 16 million Disability Adjusted Life Years (DALYs). There were 5 to 6 million Years of life lost and 5 to 10 million Years Lived with Disabilities.[9] As per World Health Organization (WHO) globally, the lifetime prevalence of epilepsy in 2019 was 7.60 per thousand population.[10] According to Global Burden of Disease (GBD) 2016 epilepsy collaborators, the global age-standardized prevalence of all active epilepsy was 6.2 per thousand population and it varied from 3.11 in Japan to 12.87 per thousand population in Cape Verde. The pooled incidence rate is sixty-one per lakh person-years. The prevalence of epilepsy varies widely around the world.[9]

Asia

Half of the world's population lives in Asia which is approximately four billion people. About twenty-three million people are suffering from epilepsy which makes about half of all cases of epilepsy worldwide. In 2017, the prevalence was lowest in Korea (2.3 per thousand population) and highest in Japan (40 per thousand population) among the Asian countries.[8]

India

The crude DALY rate due to epilepsy in India is 374 per lakh population and it is highest in Odisha (511 per lakh population) and lowest in West Bengal (215 per lakh population).[7] Previous studies in India (1988 to 2018) have reported the prevalence of active epilepsy in range of 3.6 to 7.7 per thousand population. It is higher in children.[10-12] It comprises about 20.0% of the global burden. The

people with epilepsy (PWE) ranges from 8.4 to 11.9 million and the crude prevalence has increased by 43% and age-standardized prevalence has increased by 37.0% in last three decades.[7] First-ever neuroepidemiological survey for epilepsy conducted in Vellore in 1968 reported the prevalence of 7.5 in urban and 9.8 per thousand population in rural area. The crude prevalence per thousand population was 2.5, 4.0, 5.6 and 6.5 in rural Kashmir (1986), Ballabhgarh (1986), rural Haryana (1993) and Dehradun(2008), respectively.[13] In population-based studies the standardized mortality ratio due to epilepsy ranges from 2.58 to 3.9 from urban (2010) and rural (2005) India respectively.[14]

The DALY rate contributed by epilepsy in Punjab is 433 per lakh population.[7] In 2008, A cross-sectional study conducted in rural Patiala reported period prevalence of active epilepsy (7.7 per thousand population) and lifetime prevalence of epilepsy (9.1 per thousand population). However, this study used previous definition of active epilepsy and didn't determine the treatment gap.[12] In a study among age group of 1-18 years the prevalence of epilepsy was 6.24 per thousand population in Chandigarh (2014)[15]

Epilepsy treatment gap

Though epilepsy is a treatable condition but there is huge treatment gap reported. Epilepsy treatment gap is defined as proportion of undiagnosed cases of epilepsy and PWE not receiving appropriate treatment or receiving traditional medicine among total people with active epilepsy and it is expressed as percentage.[16] This gap exceeds 75.0% in most low- income countries and 50.0% in most middle-income countries.[17] To reduce the gap WHO launched pilot projects in 2012 in four countries i.e. Ghana, Mozambique, Myanmar and Vietnam. These projects showed that up to 70.0% of PWE can remain seizure-free with the help of cost-effective anti-seizure medications, hence, improving their quality of life and participation in society.[10]

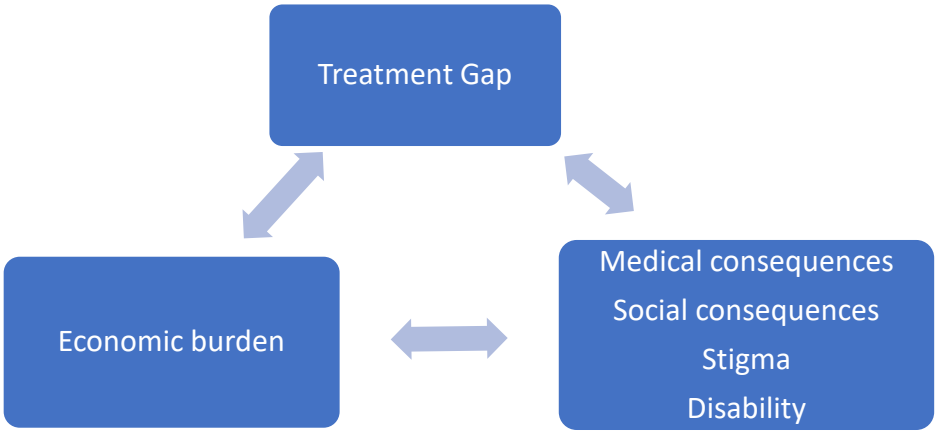
All six WHO regions had adopted declaration regarding reduction in treatment gap to increase political commitment and compliance from governments. To meet the target 3.8 of Sustainable Development Goals (SDG) globally, prevention, treatment and care for MNS conditions must be integrated into public health services. In 68th World Health Assembly (WHA) (2015) resolution on epilepsy was adopted unanimously by member states including India.[18] In 2018 political declaration was made to include mental and neurological disease under the umbrella of NCD by High Level Meeting of United Nations general assembly.[19]

Magnitude of treatment gap

The magnitude of the epilepsy treatment gap in India ranges from 40.0% in rural Rajasthan (2005) to 90.0% in rural West Bengal (1995-1996).[17] A study in Chandigarh (2014) reported treatment gap of 22.2% in1-18 year age group.[15]

Determinants of treatment gap

The problem of the treatment gap in epilepsy is magnified by the negative attitudes attached to it. Consequently, many of them are forced to live without appropriate treatment despite the availability of effective antiepileptic drugs (AEDs). It is a vicious cycle.



The diagnosis of epilepsy in a person has ramifications for the whole family. While caring for an epileptic child, parents experience a whole

wide range of emotions. It leads to the realization that person or child will need constant supervision. There is fear and uncertainty. The caregivers of people with epilepsy (PWE) need to learn about medications, deal with regular hospital visits and look out for any behavioural issues. Parents must miss work to take PWE to a clinic. Both missing work and out of pocket expenditure for healthcare needs of PWE can lead to financial troubles. Other factors which contribute to economic burden are lower socio-economic status and nuclear family.[20]

For ages, epilepsy has been associated with fear, supernatural demonic possession misunderstanding, discrimination, and societal stigma. In some societies it was linked with lunacy, weakness, and incompetency. Most of times person suffering from epilepsy and their well-wishers try to hide their medical status for as long as possible.

“He had a fever . . .
And when the fit was on him, I did mark
How he did shake. 'Tis true, this god did shake.
His coward lips did from their colour fly;
And that same eye whose bend doth awe the world
Did lose his lustre. I did hear him groan,
Ay, and that tongue of his that bade the Romans
Mark him and write his speeches in their books,
'Alas,' it cried, 'Give me some drink, Titinius',
As a sick girl”

In the Shakespeare’s play Julius Caesar act 1, scene 2 Cassius describes to Brutus about a seizure suffered by Julius Caesar in Spain. Here Cassius is trying to mock alleged seizure suffered by Julius Caesar to undermine his authority. [21]

The modern science has rejected all those claims. Being a neurological disease has brought its own fear and misperceptions with it, which has led to stigma. PWE are considered to be unreliable, not fit for employment and marriage. Their ability to fulfil their social roles is question marked. In most countries, PWE have driving restrictions. They can get driving license only after certain periods of being seizure

free. People avoid being alone with PWE because they do not know what to do in case a seizure occurs. This leads to social avoidance.[22]

After being diagnosed with epilepsy, PWE assumes a distinct 'epileptic identity'. They experience two types of stigmas - Felt stigma and Enacted stigma. In felt stigma, PWE feels shame being an epileptic and when they experience discrimination due to epilepsy it is referred as enacted stigma. PWE characterize themselves as less-dependable, less well- adjusted than individuals without epilepsy. It causes lower self-esteem and higher anxiety. Despite its enormous social and economic burden globally, epilepsy is still ignored public health problem especially among low and middle-income countries (LMIC).

Healthcare seeking behaviour

People with epilepsy (PWE) have limited social inclusion and employment opportunities. This interferes with the health-seeking behaviour. Other factors are the socioeconomic status, availability and accessibility of epilepsy services near their residence and education level. The preference for traditional or allopathic medicine, epilepsy knowledge and practices determine healthcare seeking behaviour.

Need for present study

There is a scarcity of knowledge on the determinants of treatment gap in PWE which is a hindrance in adequate utilization of health services available. In public health sector, treatment options for epilepsy are available under Mukyamantri Muft Ilaaj Yojana (MMIY)[23],and Pradhan Mantri Jan Arogya Yojana (PMJAY) but there is no separate national program dedicated to diagnosis, treatment, follow-up and rehabilitation of PWE. There is no provision of information, education or behaviour change communication to deal with stigma associated with the disease. This is despite the fact that leading medical experts have written and deliberated with government on various occasions for urgent need of a national program for prevention and control of epilepsy.

The present study is an attempt to address these above-mentioned issues in rural area because of following reasons

- There is no provision for formal training in epilepsy for primary health care providers in rural areas.
- There is lack of basic technologies for diagnosis of epilepsy like electroencephalogram (EEG).
- Only essential antiepileptic drugs (AEDs) like phenytoin, sodium valproate, carbamazepine or phenobarbital are available and none of the newer anti-epileptic drugs like lamotrigine, levetiracetam are available in primary care setting.
- There is paucity of literature regarding epilepsy treatment gap in Punjab
- Most of the studies which have been conducted in Punjab have either used old definitions, conducted in selected age group, or done in urban area which addresses the prevalence and treatment gap. Hence this study is done in rural area in all age groups and treatment gap is studied.

In the light of above discussion, this community-based study was planned to estimate the prevalence, treatment gap in and its determinants in PWE.

AIMS AND OBJECTIVES OF THE STUDY

1. To find prevalence of epilepsy in a rural area of Ludhiana.
2. To study the determinants of treatment gap in people with epilepsy.

REVIEW OF LITERATURE

Epilepsy is an age-old disease. Its symptoms and different types are described on an important manuscript of Neo-Babylonian (626-539 BC) tablet of medical diagnostic series. This tablet is made of clay and dates back 1500 - 4000 years. It is currently located in the British Museum, London. Wilson *et al* in 1990, Stol *et al* in 1993, Nils *et al* in 2000 have translated text from this tablet.[1]

Ayurveda is an ancient Indian medical literature that describes epilepsy as 'Apasmara' which means loss of consciousness or memory. Ayurvedic literature is divided into Brhattrayi and Laghutrayi and both of them includes three volumes of literature each. Out of these six volumes, Charaka Samhita, Madhava Nidana and Susruta Samhita reported aetiology, signs and symptoms, types and treatment of epilepsy. The aura was described as ApasmaraPoorva Roopa. The four types of epilepsy described were Vatika, Pattika, Kaphaja and Sannipatika.[2]

Public Health Problem

Worldwide, epilepsy imposes an enormous public health problem that leads to premature mortality and affects the quality of life. In low and middle-income countries, excess mortality is associated with a lack of access to health facilities. Quality of life of persons associated with PWE also suffers, as they have to be on high alert always due to seizures, economic resources are spent on PWE and social isolation. Social isolation can be due to overprotective behaviour of family members or discriminative treatment on the part of relatives and friends. In spite of its enormous social and economic burden epilepsy is often ignored public health problem, especially among low and middle-income countries. Due to the epidemiological transition, developing countries are facing a double burden of communicable and non-communicable diseases. However, non-communicable diseases are also on the rise in our country.

Problem statement

Murray *et al* (2012) in a systematic analysis of Global Burden of Disease observed that there is a shift in the composition of Disability-adjusted life years (DALYs) although total DALY remained stable globally. Worldwide communicable, maternal, neonatal, and nutritional disorders combined contributed to 47% of DALY in 1990 which declined to 35% in 2010 while DALY due to non-communicable disease rose from 43% to 54% during the same period. Globally 3% of DALY's were due to neurological disorders and one-fourth of which were due to epilepsy which translates to 253 DALY per lakh population in 2010.[24]

In the year 2019, Global burden of disease 2016 Neurology collaborators, found that the absolute number of DALYs due to neurological disorders is increasing. As the population is ageing there will be a rise in the prevalence of major neurological disorders. With this, there will be an increase in demand for rehabilitative and support services from the public health sector. They found that epilepsy contributed over 13.5 million DALY's which is a 9% increase since 1990. [25]

Prevalence of epilepsy

Fiest *et al* (2016) published a systematic review and meta-analysis in the official journal of the American Academy of Neurology in which the lifetime prevalence of epilepsy was 7.6 per 1000 persons. There was no change in prevalence of epilepsy when sorted by age group, study quality or gender. The highest prevalence of epilepsy is of unknown aetiology. The study pointed out the gap in various studies and called for standardization in reporting of future epidemiological studies on epilepsy.[26]

J.W.Sander in 2003 reported that Epilepsy causes a significant burden on individuals and the healthcare system. It was estimated that nearly 50 million people suffer from epilepsy. The prevalence of epilepsy across the globe was estimated to be 5 – 10 per thousand

population. It could be more than 10 per 1000 in some places. Age-specific incidence rates have changed. There was an increase in prevalence in the old age group and a decrease in the young age group.[27]

Prevalence in India

A systematic review and metanalysis of 50 studies conducted by Dhiman *et al* (2021) and reported 3.8 to 5.6 per 1,000 population pooled prevalence of epilepsy. The subgroup analysis of pooled prevalence showed before year 2000 it was 3.0 - 4.8 per thousand population and it increased to 3.5 - 5.0 per thousand population by 2010.[28]

A prospective cohort study was done on epidemiology of new onset seizures and epilepsy cases by Goel *et al* (2020) in two blocks of Uttarakhand state. After longitudinal follow-up for 3 years, the age-adjusted prevalence rate of unprovoked seizures was 623.63 cases per 100,000 of population. Age-adjusted incidence rate of epilepsy was 38.28 per 100,000 population and annual incidence of acute symptomatic seizures was 14.79 per 100,000 of population.[29]

In Epilepsy: a public health imperative (2019) World Health Organization estimates the prevalence of epilepsy in India from 3.6 to 7 per 1000 taking into account the studies conducted from 1998 to 2014 from various parts of India.[10]

National mental health survey 2015-2016 reveals the overall prevalence of screener positive epilepsy across NMHS states is 0.3% while that of Punjab is 0.7%.[30]

Hara *et al* (2015) studied epilepsy in rural Patiala by the door-to-door survey in 2008 in which prevalence rate comes out to be 7.67/1000 which was similar to that of an urban area but less than prevalence rate of remote rural area. For categorization of epilepsy this study mainly relied upon history and clinical examination.[12]

Prevalence of epilepsy in India

AUTHOR	YEAR	PLACE	PREVALENCE (Per 1000 population)
Goel *et al* [29]	2020	Uttarakhand	6.2
Panagariya *et al*[11]	2017	Jaipur, Rajasthan	1.1
Hara *et al* [12]	2008	Patiala, Punjab	7.7
Pandey *et al*[15]	2014	Chandigarh	6.2
Singh *et al* [31]	2012	Jamalpur, Punjab	7.2
Raina *et al* [32]	2012	RS Pura, Jammu	2.0
Shah *et al [33]*	2009	Kashmir	3.2
Goel *et al* [34]	2009	Dehradun, Uttarakhand	7.5
Surekha and Surekha[35]	2007	Rajasthan	3.0
Rajshekhar *et al*[36]	2006	Tamil Nadu	3.8
Murthy *et al*[37]	2004	Andhra Pradesh	6.2
Saha *et al* [38]	2003	West Bengal	3.6
Radhakrishnan *et al* [39]	2000	Kerala	4.9
Pal *et al* [40]	1998	West Bengal	3.2
Das and Sanyal[41]	1996	West Bengal	3.1
Premarajan *et al*[42]	1993	Pondicherry	1.3

Pandey *et al* (2014) studied the prevalence of epilepsy in 1–18-year age group in the union territory of Chandigarh by two-stage cluster sampling technique. Standard definitions provided by the international league against epilepsy were used to define cases and calculation of treatment gap in the community. The prevalence rate for epilepsy in 1-18-year age group came out to be 6.24/1000 population.[15]

Family history of epilepsy

In study by Pandey et al (2014), 13 % of the subjects had positive family history of epilepsy.[15] Gupta and Desai (2017) studied epilepsy profile in a tertiary care hospital of western India and found that 3.36% of the subjects had positive family history of epilepsy.[43]

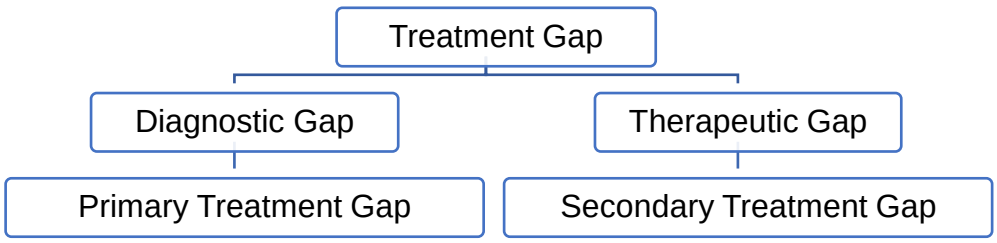
WHO's initiative

At least half of the people in the world do not receive the health services they need. To create awareness, World Health Organization has chosen World Health Day theme for the year 2018 and 2019 consecutively as "universal health coverage". Every aspect comprising of health promotion, prevention, treatment and palliative care should be available to everyone everywhere. We must improve the accessibility, safety and affordability of primary health care for the masses. Health workers have to educate patients at the community level on taking care of their health.[44]

Treatment Gap

Treatment of a disease is any intervention the ultimate goal of which is to restore health. The treatment gap in epilepsy is the proportion of people with active epilepsy who either lack diagnosis or appropriate treatment regimen in a given population at a given point of time. It is expressed in percentage.

Brodie *et al* (2012) reported that treatment options for people with epilepsy were available since the early 20th century. Moreover, 75% have treatable epilepsy and can lead near-normal lives on an appropriate regimen, yet 85% of people with epilepsy do not get appropriate treatmentdue to various reasons. [45]



History of Treatment Gap

Ellison *et al* (1987) gave the concept of treatment gap. It was defined as the proportion of people with active epilepsy in a given population in the given time period of one day who were not receiving AED. The formula given to measure treatment gap in percentage was as follows

$$\text{Treatment gap} = \frac{\text{(Estimated prevalence of epilepsy- No. of patients receiving AED) *100}}{\text{Estimated prevalence of epilepsy}}$$

Shorvon and Farmer (1988) coined the term Epilepsy Treatment Gap. In Ecuador, Pakistan and Philippines epilepsy treatment gap was observed to be more than 80 percent using the above formula. They advocated for using a screening questionnaire in a community for a more positive response as compared to clinical examination.[46]

Meinardi *et al* (2001) in ILAE Commission report on treatment gap in epilepsy defined the seizure treatment gap which included both diagnostic and therapeutic gap. Beside defining treatment gap, measurement of treatment gap, its causes, and potential ways to reduce it were also elicited by the author. To provide indirect measure of epilepsy treatment gap and people with epilepsy who were on medicine two separate formulas were described.[47]

According to the systematic review of 74 peer-reviewed publications conducted by Meyer *et al* in 2010, it was estimated that epilepsy treatment gap exceeds 75 percent in most low-income countries and 50 percent in middle income and 10 percent in high-income countries. It is more in rural areas as compared to urban areas. It revealed stark disparities both between and within countries in care of people with epilepsy. Epilepsy is a common neurological disorder with potentially serious health and social consequences if left untreated. Its diagnosis, effective and inexpensive treatment is available which can be prescribed by primary care physician.[17]

In both developed and developing countries, there is the negative public attitude towards epilepsy and political neglect of hidden and

misunderstood disorder. Three international agencies World Health Organization (WHO), International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) in 1997 jointly initiated Global Campaign Against Epilepsy. This collaboration is first of its kind in neurology. It was primarily for developing countries. Its mission was to improve availability, accessibility and acceptability of treatment modalities and preventive services as well. This initiative involves global, national and regional level inter-related activities.[10]

Global Campaign Against Epilepsy (GCAE) proved to be a powerful tool for intervention in Epilepsy Treatment Gap (ETG). The ultimate goal of GCAE was to close ETG. 'Bringing epilepsy out of shadows' campaign found that there was a lot of under-reporting of people with epilepsy in community settings due to stigmatization. In addition to stigma, various social issues also lead to fewer job opportunities which lead to emotional and financial hardships. The problem of the treatment gap in epilepsy is magnified by the stigma and negative attitudes attached to it. These factors play an important role in determining the adherence to treatment among people with epilepsy.[48]

At 68th World Health Assembly in 2015, a resolution on epilepsy was adopted calling for the "need for coordinated action at the country level' to address its health, social and public knowledge implications. In people with epilepsy risk for premature death are two times more in high-income countries and six times more in middle and low-income countries in comparison to the general population. World Health Organization and its key partners are drawing the attention of its member countries with the message of "The time to act is now" to address the burden of epilepsy through the public health system. Many steps to improve epilepsy care like strengthening effective leadership and governance, improving the provision of epilepsy care, increased access to medicines, raising public awareness and education and strengthening of health information and surveillance system are recommended.[18]

Risk factor analysis was done by Mbuba *et al* (2012) in Kilifi, Kenya through cross sectional survey and it was observed that 26% of the total subjects never sought treatment for epilepsy. The epilepsy treatment gap was found to be 62.4%.[49]

Treatment Gap in India

Srivastava *et al* (2021) conducted a study in rural Pune and reported a treatment gap of 45.5% in 2 months to 18 years of age.[50] A review article by Amudhan, Gururaj and Satishchandra (2015) included 57 previous studies. It reported a epilepsy treatment gap of 22% to 95% in India.[51]

Pandey *et al* (2014) studied treatment gap among children in age group of 1-18 years and revealed it was 22.2% among subjects which was very low as compared with other studies from India. This low treatment gap was attributed to easily accessible health care facilities in and around the city.[15]

Panagariya *et al* (2017) revealed 18.8% of treatment gap in Jaipur. Epilepsy was non-curable for 15% of the subjects.[11]

Following are the previous studies which were conducted from door to door in the community and included all age groups and also reported treatment gap in study subjects.

Author	**Year of study conducted**	**Place**	**Treatment gap (%)**
Sureka and Sureka[35]	2005	Rural Rajasthan	40
Radhakrishnan *et al* [52]	1996-1997	Semi-urban Kerala	38
Mani *et al* [53]	1990-91	Rural and tribal Rajasthan	78

Determinants of treatment gap

Srivastava *et al* (2021) reported the affordability and accessibility of health care facility, healthcare seeking behaviour, availability of local

resources, socio-economic status and knowledge about epilepsy as the determinants of treatment gap in subjects 2 months to 18 years of age.[50]

Amudhan, Gururaj and Satishchandra (2015) reported the predisposing factors for treatment gap includes rural area, female gender, illiteracy and low socioeconomic status. The reasons for therapeutic gap include non-affordability, marital disharmony, employment status and frustration due to chronic nature of disease.[51]

Knowledge about epilepsy among teachers lead to worsening of academic success among PWE. Children with epilepsy experience drowsiness and behavioural problems their coping abilities are limited. It can lead to discontinuation of education. PWE have to face discrimination at jobs. Employers have substantial reluctance to employ people with epilepsy. There could be increased absenteeism among PWE either due to seizures or due to visit to health care facility. PWE have difficulty holding on to one job and have to avoid dangerous jobs including heavy machinery, driving, near water or fire.

According to Mbuba *et al* (2012), people with epilepsy were less likely to seek treatment if they had traditional animistic religious beliefs, had negative attitudes about biomedical treatment, distance between health care facility to home was 20kms or more, reported paying for AEDs, had epilepsy for longer than 10 years, had learning difficulties and had focal seizures.[49]

Das *et al* (2007) studied socio-economic factors leading to discontinuation of anti-epileptic treatment in epilepsy clinic of Burdwan Medical college and hospital. Out of total subjects who discontinued the medications, 99% of the subjects couldn’t continue due to financial constraints as large amount of their income were being expended for the cost of treatment and significant number of working days lost to attend the clinic. The other important reasons observed in the study were marital disharmony due to divorce or separation, unavailability of drugs, presence of other comorbid psychiatric illness, adverse events

of drugs and polytherapy were other reasons cited for discontinuation of treatment.[54]

Shorvon and Farmer (1988) reported community perceived causes of epilepsy as supernatural (will of God, visiting cemeteries, witchcraft), environmental (climate, phases of the moon), physical (bad behaviour, certain disease, brain damage) and psychological (guilt, worry, anger, tendency to think too much).[46]

Interventions to reduce treatment gap

Panagariya *et al* (2018) had reported that due to the availability of epilepsy services in rural area, presence of training in neurology and health policies of government had reduced treatment gap among PWE in rural Jaipur.[11]

To ameliorate the treatment gap political commitment for providing resources like essential drug supply and help to create awareness among community is needed. Interventions to close this treatment gap makes economic sense as well as literacy, income generation program, patient's perceptions, social relationships in which patient is embedded and their cultural practices concerning epilepsy should be addressed. Education, training of health workers and full integration with community health delivery system were few factors enumerated by Meinardi *et al* (2001).[47]

MATERIAL AND METHODS

Nature of Study

The present study "**Prevalence of epilepsy and determinants of treatment gap in people with epilepsy in rural Ludhiana**" is a community based cross-sectional study.

Study area

The study was carried out in the field practice area of the Rural Health Training Centre (RHTC) located at village Pohir, Block Dehlon, District Ludhiana, Punjab, India. This centre is an integral part of the Department of Community Medicine, Dayanand Medical College and Hospital, (DMCH) Ludhiana.

RHTC Pohir caters to a population of 31043. It comprises of 15 villages. These villages are Pohir, Jagera, Rangian, Gopalpur, Saharan-Majra, Jhammat, Bhikhi, Khattra, Rurka, Khera, Siahar, Lehra, Pandher-kheri, Kilahans and Kalahar. (Half-yearly report of RHTC-Pohir-30th June 2019)

In these villages, home-based comprehensive health care is provided by Multipurpose health workers (MPHW) male and female working under the Department of Community Medicine, DMCH. They are assisted by community health workers who belong to the same village. A folder for each family is maintained by the MPHW allotted to that village and kept at RHTC. These folders include individual cards, one for each family member e.g., under-five card, senior citizen card, eligible couple card, general card. These are regularly updated. These cards don't include information on epilepsy.

Ethical issues and Informed consent

The study subjects were given all necessary information regarding the present study and data was collected from willing subjects after informed consent. The subjects who had any misconceptions about epilepsy were provided medically accurate information. The

counselling regarding the diagnosis of epilepsy, duration of treatment needed and drug of choice was done by the consultant Neurologist. The subjects were administered portable electroencephalogram (EEG) free of cost wherever it was needed for supportive evidence.

The study protocol was submitted to the Institutional ethics committee of the institute for which approval was granted.

Source of Data

All Individuals residing in the field practice area of the RHTC Pohir were studied.

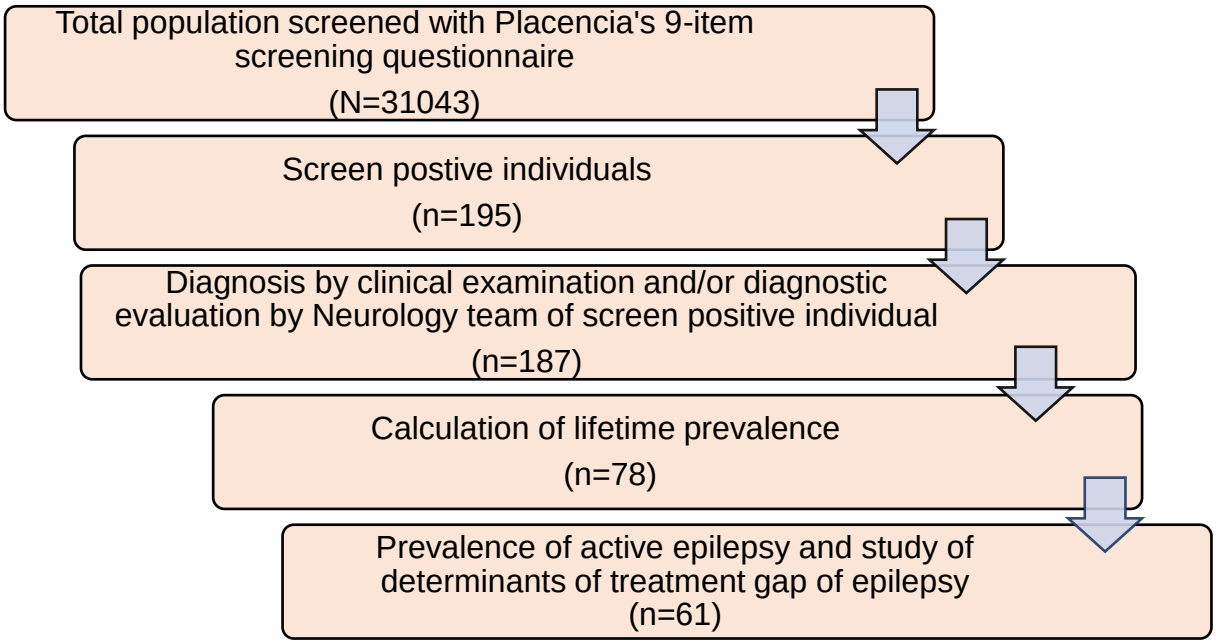
METHOD OF COLLECTION OF DATA

INCLUSION CRITERIA

The whole of the population residing in the study area.

EXCLUSION CRITERIA

1. Non-Co-operative subjects
2. Subjects who refused to participate.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Diagnosis by clinical examination and/or diagnostic evaluation by Neurology team of screen positive individual
(n=187)
Calculation of lifetime prevalence
(n=78)
Prevalence of active epilepsy and study of determinants of treatment gap of epilepsy
(n=61)

SAMPLING TECHNIQUE:

The whole population residing in the study area irrespective of age, gender, caste was eligible for screening. The investigator visited all households (n=6212) of these 15 villages door to door. The screening was done by the investigator with help of MPHW of the concerned village. Their age and gender were also recorded along with the administration of the screening questionnaire.

A 9-item screening questionnaire developed by Placencia in Ecuador was used in this study as a screening tool.[55] The permission to use this screening tool and to translate it into local vernacular language was sought from Dr. Marcelo Placencia by email. This questionnaire has been already validated for epidemiological studies of epilepsy in the community.

The screening tool was administered to all members of the family available at home at the time of visit by the investigator. For the members of the household who were not at home at the time of visit, the questionnaire was filled with help of senior-most family members available at home. Two repeat visits were done and three households were found locked at the time of third visit and were excluded from the screening. For the children, adolescents, subjects suffering from mental disease and subjects who were not competent to give consent or relevant information, screening was done with the help of their parents or the next available guardian or caregiver.

The screened positive individuals (n=195) were asked to report at RHTC Pohir on pre-informed days. The reported subjects were evaluated by a team from the Department of Neurology of this institution. The team constituted a Neurologist, DM resident, Electroencephalogram (EEG) technician, Research assistant along with a portable EEG machine from the Indian Institute of Technology - Ropar. The diagnosis of epilepsy was done by the consultant Neurologist. The diagnosis was based on clinical history, examination,

previously available reports and wherever necessary EEG was done for supportive evidence.

The subjects diagnosed to have active epilepsy (n=61) formed the second set of samples. Home visits were done by an investigator for further detailed study of their demographic profile, present/past medical history, family/personal history, menstrual/obstetric history and questionnaire determining epilepsy treatment gap of PWE.

Operational definitions:

Active epilepsy: It is defined as individuals taking regular treatment with anti-seizure medicines or when the most recent seizure has occurred within the last 5 years.[4]

Lifetime prevalence: The risk of having epilepsy at some point during the lifetime; it is used to estimate the cumulative incidence of epilepsy.[10]

Point prevalence: The number of cases of active epilepsy cases, divided by the study population on that day (active cases per 1000 population).[10]

Treatment gap: The difference in the proportion of people with active epilepsy who should be on appropriate treatment and the PWE who are treated appropriately in a given population at a given point of time. It can be primary (diagnostic) or secondary(therapeutic) and expressed as percentage.[47]

Primary treatment gap is also known as the diagnostic gap. It has been defined as people with epilepsy (PWE) who have never been diagnosed as epileptic according to internationally recommended guidelines by allopathic doctors.[47]

Secondary treatment gap is also known as the therapeutic gap. It has been defined as a PWE who after diagnosis has either altogether stopped taking the anti-epileptic drug or is not taking appropriate

treatment as per recommended guidelines of drug of choice, dosage, or duration.[47]

Appropriate Treatment is the diagnosis of the type of epilepsy and its underlying cause and treatment regimen according to international standards.[47]

Procedure of data collection

The aim of the study was explained to every subject and confidentiality of information was assured. The questionnaire is divided into two parts:

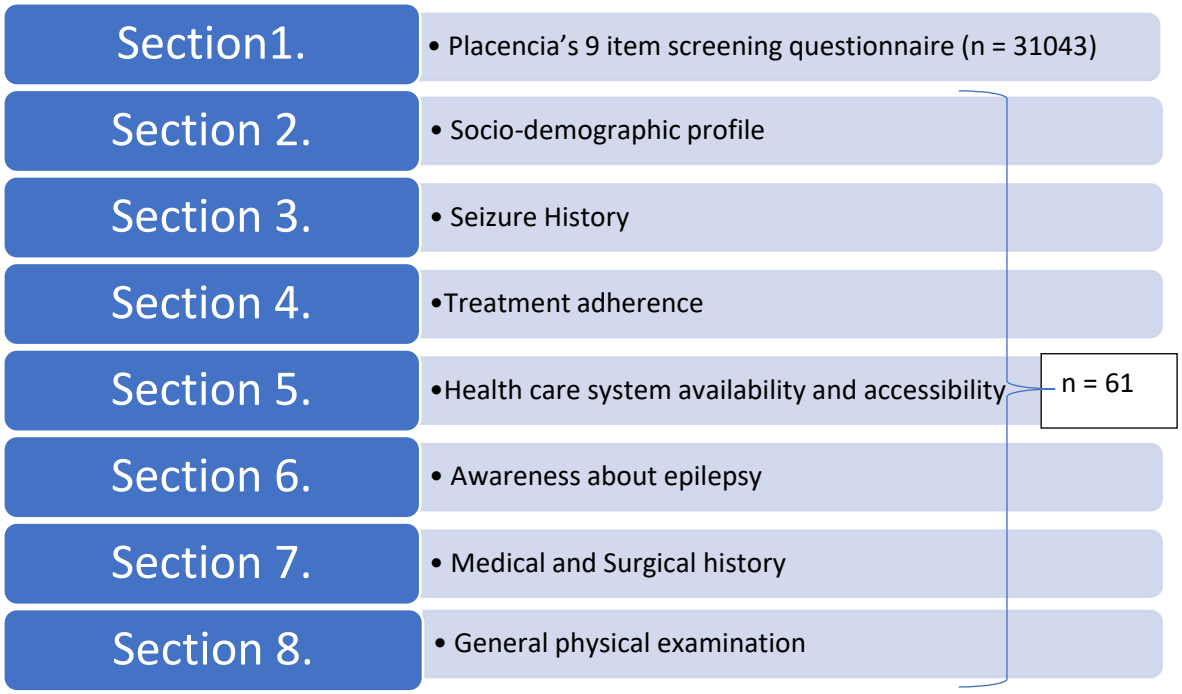
- Part I includes Section 1 of the questionnaire. It was applied to the whole population of 15 villages (n=31043). Placencia's 9 item screening questionnaire was applied to 31043 subjects. Out of these 195 were screen positive individuals. These 195 individuals were examined by the neurology team of this institute and 61 subjects were diagnosed with active epilepsy and 17 had epilepsy at some point during their lifetime.
- Part II includes section 2 to section 8. It was applied to diagnosed cases of epilepsy (n=61). The information was collected through a semi-structured proforma by visiting the house of PWE.

PILOT STUDY

A pilot study was carried out in October 2019 to test the feasibility of the study and the validity of the proforma. The study was done on 30 subjects in the village Lehra of the field practice area of RHTC Pohir. As per the pilot study, it was felt that no change was required in the proforma and study was feasible.

STUDY INSTRUMENTS IN DETAIL

The study instrument is divided into 8 sections:



Section 1: Placencia's 9 item screening questionnaire

It was validated in Ecuador in 1992 for epidemiological studies of epilepsy in the community. It has 9 questions to be asked to a subject by the investigator. It is divided into two sections. Both questions 1 and 2 must be affirmative to render the subject positive AND/OR any question 3 to 9 if affirmative renders the subject positive.

Section 2: Socio-demographic profile

This included the details of subjects like name, age, gender, occupation, address and working or not, contact number, religion, caste and ethnicity. Socio-economic assessment by Modified Udai Pareek Scale was used to allot the following grading to households.[56]

Total score	Class	Socio-economic class grading
>43	Upper class	I
33-42	Upper middle class	II
24-32	Middle class	III
13-23	Lower middle class	IV
<13	Lower class	V

Section 3: Seizure history

It included self-reported duration since first and last seizure, frequency and pattern of current and prior seizures. The preference of the type of treatment of subjects with active epilepsy or their caregivers was inquired. The health-seeking behaviour at the time of first and last seizure, detailed treatment history about the number of different antiepileptic drugs prescribed, frequency of medicine and name of medicines and reasons for stopping the treatment were recorded.

Section 4: Treatment adherence

In this section, questions were asked to study the adherence to prescribed treatment among people with active epilepsy. This included questions asking them about forgetfulness or any other reason for skipping anti-epileptic medicine. This was applied to

- PWE who were put on treatment by the Neurologist of this institute. They were followed up after two months of prescribing treatment.
- PWE who were already taking the anti-epileptic drugs.

Section 5: Healthcare system availability and accessibility

In this section, a self-structured questionnaire was used to inquire about healthcare system availability and accessibility. The questions regarding the type of health facility availed for epilepsy management, availability of doctor at the time of their visit to the health care facility,

the distance between home and the health facility, mode of transport used to reach there, the person accompanying them to the healthcare facility, the duration for which medicines were dispensed, time patients had to spend at the health facility were recorded.

Section 6: Awareness about epilepsy

The awareness of epilepsy was determined among people with active epilepsy and/or their caregivers. This included questions asking if PWE or caregivers had heard about epilepsy before their diagnosis, the cause of their epilepsy, and whether they believed that the prescribed anti-epileptic drug would control epilepsy.

Section 7: Medical and surgical history

It included four subsections.

- In the first subsection, detailed co-morbidities and their concomitant treatments, past medical and surgical history was recorded.
- In the second subsection, family history regarding epilepsy and consanguineous marriage among parents of people with epilepsy was recorded.
- In the third subsection, sleeping patterns, diet, substance abuse and health insurance were asked.
- In subsection four, menstrual history, its relation to seizure, number of total conceptions, miscarriages and live children were recorded.

Section 8: General Physical Examination

It included height, weight, blood pressure and calculation of body mass index (BMI).

- Height was measured using a non-stretchable, flexible and narrow measuring tape. Subjects were asked to stand along a wall with feet joined at the ankle and heels, buttock, shoulder and back of head touching the wall in such a way that the opening of the external auditory canal was at the right angle to

the wall. In subjects who were not able to stand straight, their length was recorded in a lying down position.[57]

- Weight was recorded with a standard non-digital weighing machine which was standardized by putting a known weight over it. The weighing scale was put on a flat surface and the subject was asked to stand on it without shoes and minimum clothes at the centre and weight was recorded in Kilograms. In subjects who were bedridden or not able to stand still for weight measurement their last known weight from the caregiver was recorded.[57]
- BMI was calculated using the following formula
  BMI= Weight (kilogram)/Height^2 (meter^2) and classified per the WHO-Asian classification of BMI. The classes included underweight (<18.5 Kg/m2), normal (18.5-22.9), overweight (23-24.9) and obesity (≥25).[58]

STUDY DURATION

The study was conducted from 1st March 2020 to 28th February 2021.

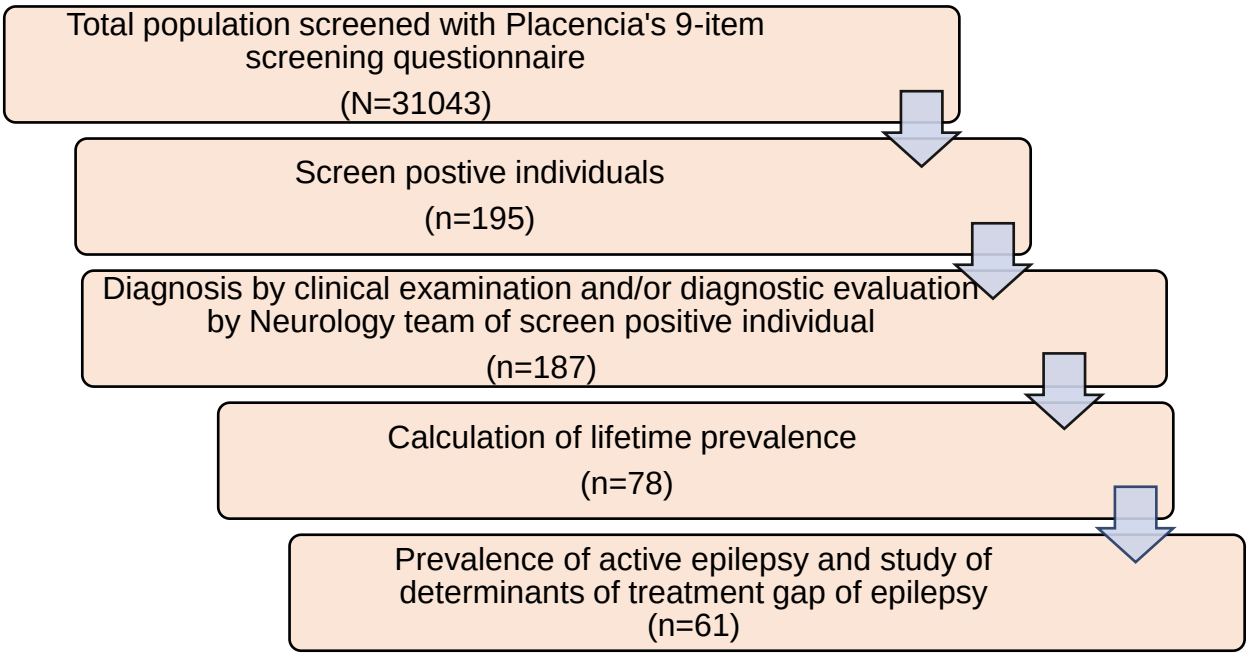
STATISTICAL ANALYSIS

Data was described in terms of frequencies (number of cases), relative frequencies (percentages), range and mean ± standard deviation (±SD). For comparing categorical data, the Chi-square ($\chi 2$) test was performed, and the Fischer-exact test was used when the expected frequency was less than 5. A probability value (p-value) less than 0.05 was considered statistically significant. All statistical calculations were done using SPSS (Statistical Package for the Social Science) SPSS 26.

OBSERVATIONS AND RESULTS

The present study, "**Prevalence of epilepsy and determinants of treatment gap in people with epilepsy in rural Ludhiana",** is a community-based cross-sectional study. This study was carried out in the field practice area of the Rural Health and Training Centre (RHTC) of the Department of Community Medicine, Dayanand Medical College and Hospital, Ludhiana, Punjab. RHTC Pohir provides comprehensive home-based health care to 15 villages.

The population (31043) residing in study area were administered Placencia's 9-item screening questionnaire.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(n=78)
Prevalence of active epilepsy and study of determinants of treatment gap of epilepsy
(n=61)

Observations have been categorised under following headings:

Section 1: Population and sample characteristics of study population

Section 2: Prevalence of epilepsy and their sociodemographic profile

Section 3: Determinants of epilepsy treatment gap

Section 1: Population and sample characteristics

Table 1: Distribution of study population according to age

N= 31043

Age (years)	Study population (%)
< 10	3295 (10.6)
10-19	4455 (14.4)
20-29	5793 (18.7)
30-39	5257 (16.9)
40-49	4299 (13.9)
50-59	3633 (11.7)
60-69	2350 (7.5)
70-79	1369 (4.4)
≥ 80	592 (1.9)
Total	31043
Mean age ± SD	54.5 ± 13.4 years

Table 1 shows the age-wise distribution of the study population. A total of 31043 persons were screened with Placencia's screening questionnaire. It was seen that 7750 (25%) persons were < 20 years old and 18982 (61.2%) were in the age group of 20 to 59 years of age. Only 4311 (13.8%) persons were ≥ 60 years of age. The maximum number of study participants were in the age group of 20-29 years. The mean age of study population was 54.5 ± 13.4 years.

Table 2: Distribution of study population according to gender

N= 31043

Gender	Study population (%)
Male	16452 (53.0)
Female	14591 (47.0)
Total	31043

Table 2 shows the gender-wise distribution of the study population. In a total of 31043 study population screened, there were 16452 (53.0%) males and 14591 (47.0%) females.

Table 3: Age and gender wise distribution of study population

N= 31043

Age (years)	Male (%)	Female (%)
< 10	1704 (10.4)	1591 (10.9)
10-19	2457 (14.9)	1998 (13.7)
20-29	3162 (19.2)	2631 (18.0)
30-39	2843 (17.2)	2414 (16.6)
40-49	2241 (13.6)	2058 (14.1)
50-59	1817 (11.1)	1816 (12.5)
60-69	1192 (7.3)	1158 (7.9)
70-79	713 (4.3)	656 (4.5)
≥ 80	323 (2.0)	269 (1.8)
Total	16452	14591

The age and gender-wise distribution of the study population shows that the maximum number of males and females, 3162 (19.2%) and 2631 (18.0%), respectively, were in the age group of 20-29 years. The numbers of males and females, 323 (2.0%) and 269 (1.8%), respectively, were the minimum in the ≥80 year old age group among the study population.

Table 4: Screen positive individual according to Placencia's 9 item screening questionnaire for epilepsy

Total subjects screened	31043
Screen positive individuals	195 (0.6%)

Placencia's 9-item screening questionnaire was developed in Ecuador. It has been previously validated for the screening of epileptic seizures in epidemiological studies. It was administered to a total population of 31043 for epilepsy screening, and 195 were screened as positive individuals.

Figure 1: Distribution of screen positive persons as per clinical and/ or diagnostic evaluation by neurologist

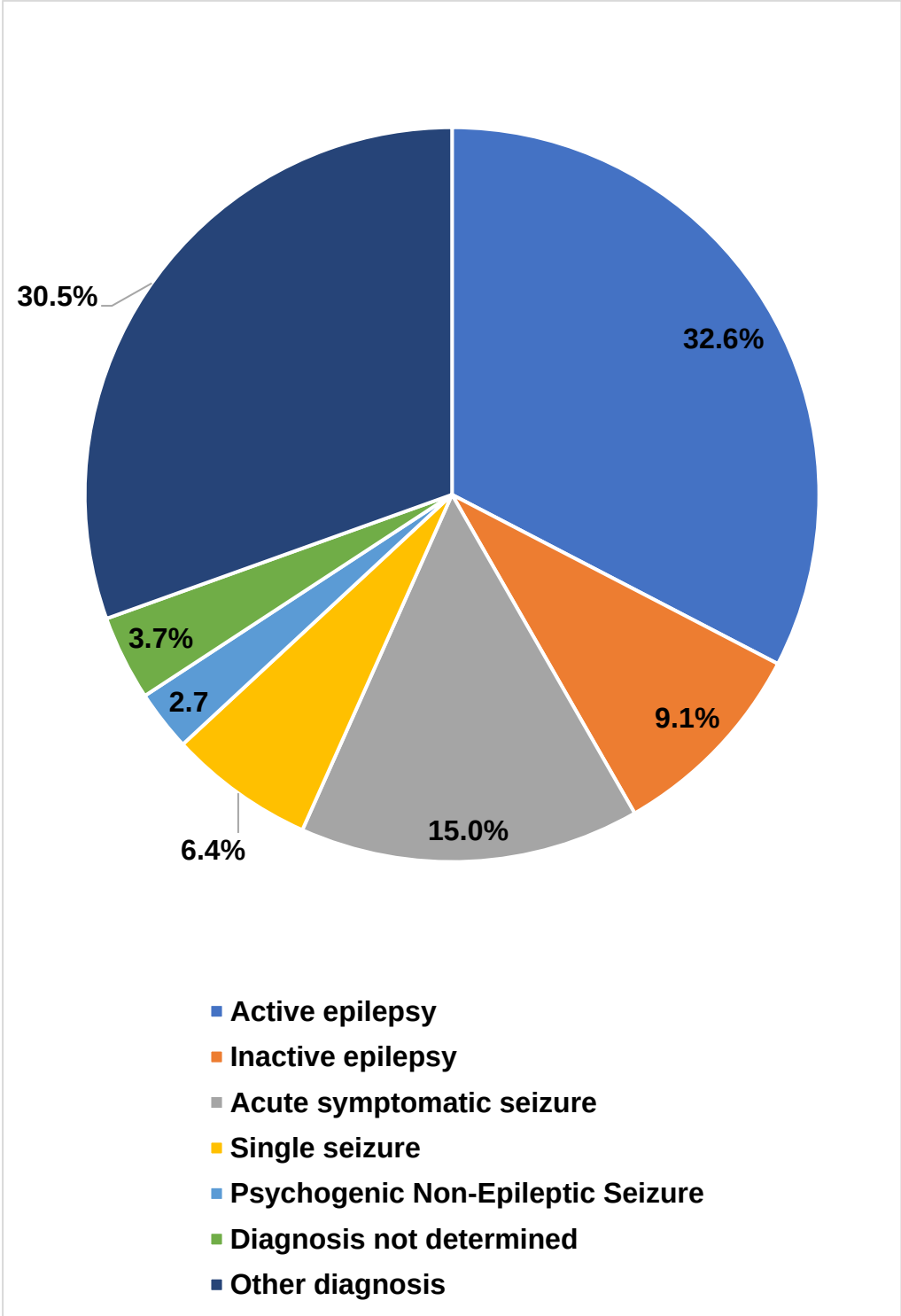

Table 5: Distribution of screen positive persons as per clinical and/ or diagnostic evaluation by neurologist n=187*

Classification	Number of Cases (%)
Active epilepsy[a]	61 (32.6)
Inactive epilepsy[b]	17 (9.1)
Acute symptomatic seizure[c]	28 (15.0)
Single seizure[d]	12 (6.4)
Psychogenic Non-Epileptic Seizure[e]	5 (2.7)
Diagnosis not determined[f]	7 (3.7)
Other diagnosis	57 (30.5)

**Out of 195 screened positive individuals, four refused to participate and the other four died before clinical evaluation.*

It was observed that out of 187 screen positive and clinically evaluated individuals, 61 (32.6%) were diagnosed with active epilepsy, 17 (9.1%) with inactive epilepsy, 28 (15.0%) with acute symptomatic seizure, 12 (6.4%) with single seizure, and 5 (2.7%) with psychogenic non-epileptic seizure. The diagnosis of 7 (3.7%) of them was indeterminate, whereas 57 (30.5%) of them had other diagnosis.

Definitions

[a]Active epilepsy is defined by regular treatment with antiseizure medicines or when the most recent seizure has occurred within the last 5 years.[4]

[b] Inactive epilepsy is said to be present when seizures no longer occur and no antiseizure medications have been employed for the last five years.[4]

[c] *Beghi et al.* define an acute symptomatic seizure as a clinical seizure occurring at the time of a systemic insult or in close temporal association with a documented brain insult.[59]

[d] ILAE recommends that seizures clustering within 24 hours should be considered a single seizure.[4]

[e] Psychogenic non-epileptic seizures are attacks that may look like epileptic seizures but are not epileptic and instead are caused by psychological factors. Sometimes a specific traumatic event can be identified.[60]

[f] The cases in which it was not possible to determine whether the seizures were caused by epilepsy or by another disease based on the clinical history and diagnostic tools available were labelled as “diagnosis not determined”.

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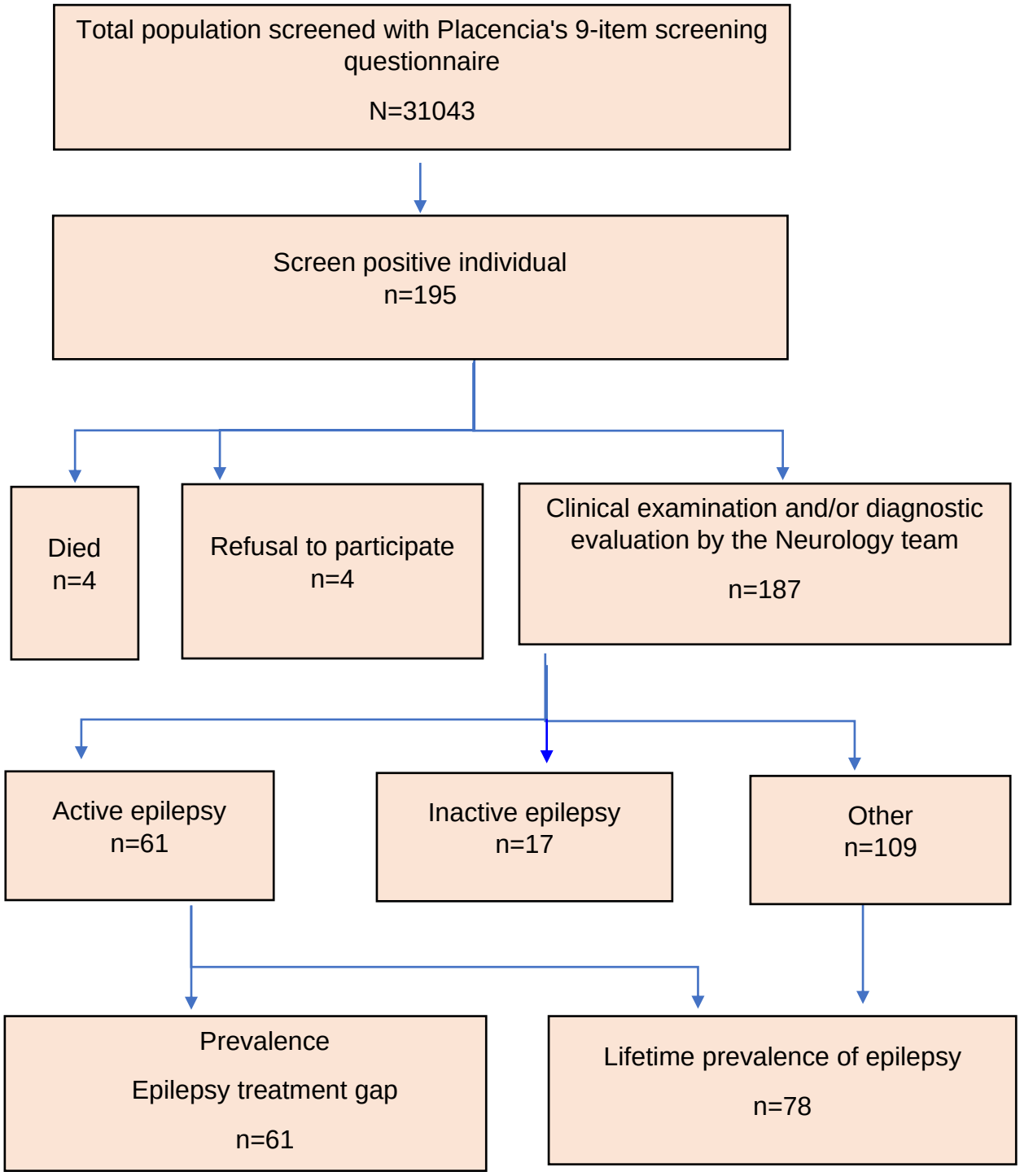
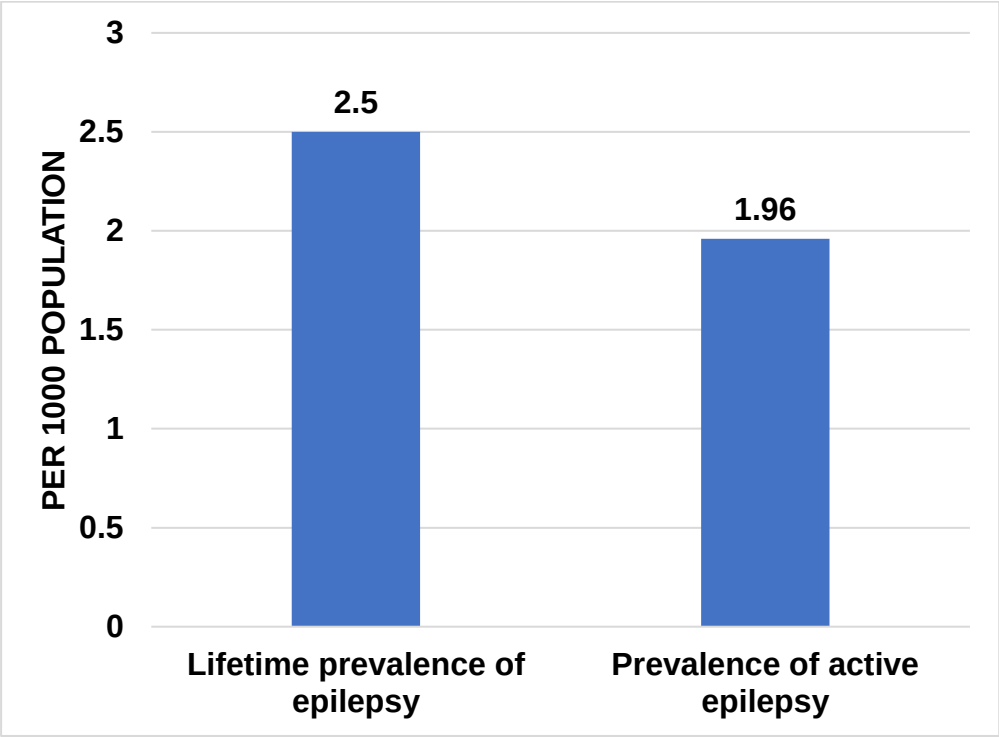

Total population screened with Placencia's 9-item screening questionnaire
N=31043
Screen positive individual
n=195
Died
n=4
Refusal to participate
n=4
Clinical examination and/or diagnostic evaluation by the Neurology team
n=187
Active epilepsy
n=61
Inactive epilepsy
n=17
Other
n=109
Prevalence
Epilepsy treatment gap
n=61
Lifetime prevalence of epilepsy
n=78

Figure 2: Prevalence of epilepsy



SECTION 2: PREVALENCE OF EPILEPSY

Table 6: Prevalence of epilepsy **N=31043**

	Number of subjects	Prevalence
Lifetime prevalence of epilepsy[a]	78	2.5
Prevalence of active epilepsy[b]	61	1.96

Table 6 shows that lifetime prevalence of epilepsy was 2.5 per 1,000 study population, while the prevalence of active epilepsy was 1.96 per 1,000 study population.

Definitions:

[a] "Lifetime prevalence of epilepsy" is defined as the risk an individual has of developing epilepsy at some point during his or her lifetime. It includes both active epilepsy and inactive epilepsy.[10]

[b] As defined by ILAE (2014), a person is said to be suffering from active epilepsy when the most recent seizure has occurred within the last five years or when the person is seizure-free while on regular anti-seizure medicines.[4]

Table 7: Age-specific lifetime prevalence of epilepsy n=78

Age (years)	Number of subjects (%)	Prevalence
< 10	9 (11.5)	2.7
10-19	8 (10.3)	1.8
20-29	18 (23.1)	3.1
30-39	13 (16.7)	2.5
40-49	13 (16.7)	3.0
50-59	6 (7.7)	1.7
60-69	5 (6.4)	2.1
70-79	4 (5.1)	2.9
≥ 80	2 (2.6)	3.4
Total	78	2.5

**Chi-square=3.728, df=8, p=0=881, Non-significant*

The age-specific lifetime prevalence of epilepsy was found to be highest at 3.4 per 1,000 persons in the age group of ≥ 80 years, followed by 3.1 per 1,000 persons aged 20-29 years. Whereas the lowest prevalence was seen in the age groups of 50-59 years and 10-19 years (1.7 and 1.8, respectively).

Table 8: Age and gender-wise distribution of Life-time prevalence of epilepsy n= 78

Age (years)	Male (number of subjects)	Female (number of subjects)
< 10	2.9 (5)	2.5 (4)
10-19	2.0 (5)	1.5 (3)
20-29	3.8 (12)	2.3 (6)
30-39	1.4 (4)	3.7 (9)
40-49	3.6 (8)	2.4 (5)
50-59	1.1 (2)	2.2 (4)
60-69	2.5 (3)	1.7 (2)
70-79	5.6 (4)	0.0 (0)
≥ 80	3.1 (1)	3.7 (1)
Total	2.7 (44)	2.3 (34)
	Chi-square=8.318, df=8, p=0.403, Non-significant	Chi-square=4.603, df=8, p=0.799, Non-significant

In Table 8, it was seen that the overall age and gender-specific life-time prevalence of epilepsy was 2.7 per 1,000 among males and 2.3 per thousand among females. In the age groups of 30-39, 50-59, and ≥ 80 years, the prevalence was higher among females.

The highest age and gender-specific lifetime prevalence of epilepsy was seen in the 70–79 year old (5.6 per 1,000) age group among males and the 30–39 year age group, as well as ≥ 80 years (3.7 per 1,000) among females.

Table 9: Age-specific prevalence of active epilepsy n = 61

Age (years)	Number of subjects (%)	Prevalence
< 10	9 (14.8)	2.7
10-19	7 (11.5)	1.6
20-29	13 (21.3)	2.2
30-39	11 (18)	2.1
40-49	10 (16.4)	2.3
50-59	3 (4.9)	0.8
60-69	3 (4.9)	1.3
70-79	4 (6.5)	2.9
≤ 80	1 (1.6)	1.7
Total	61	1.96

Chi-square=5.533, df=8, p-value=0.699, Non-significant

The prevalence of active epilepsy in the current study was 1.96 per thousand study participants. It was the highest (2.9 per 1,000 study population) in the 70-79 age group and the lowest (0.8 per 1,000 study population) in the 50-59 age group.

Table 10: Age and gender wise prevalence of active epilepsy

n=61

Age (years)	Male	Female
< 10	2.9 (5)	2.5 (4)
10-19	1.6 (4)	1.5 (3)
20-29	2.5 (8)	1.9 (5)
30-39	1.4 (4)	2.9 (7)
40-49	2.7 (6)	1.9 (4)
50-59	0.6 (1)	1.1 (2)
60-69	1.7 (2)	0.9 (1)
70-79	5.6 (4)	0.0 (0)
≥ 80	0.0 (0)	3.7 (1)
Total	2.1 (34)	1.9 (27)
	Chi-square=9.308, df=8, p=0.317, Non-significant	Chi-square=4.85, df=8, p=0.774, Non-significant

According to Table 10, the overall age and gender-specific prevalence of active epilepsy was 2.1 per 1,000 males and 1.9 per 1,000 females. In the age groups of 30-39, 50-59, and ≥80 years, the prevalence was higher among females as compared to males.

The highest age and gender-specific prevalence of active epilepsy among males was 5.6 per 1,000 in the 70–79 year age group, followed by 2.9 per 1,000 males in the <10 year age group. In the female study population, the highest prevalence was 3.7 per 1,000, seen among those ≥80 years of age, followed by 2.9 per 1,000 in the 30–39 year age group.

Table 11: Distribution of subjects according to religion n=61

Religion	Number of subjects (%)
Sikh	56 (91.8)
Hindu	3 (4.9)
Muslim	2 (3.3)
Christian	-
Total	61

It was observed that majority 56 (91.8%) subjects were Sikhs. There were 3 (4.9%) Hindus and 2 (3.3%) Muslims among study subjects.

Table 12: Distribution of subjects according to marital status

n=61

Marital status	Number of subjects (%)
Unmarried	29 (47.5)
Married	28 (45.9)
Widowed/Divorced	4 (6.6)
Total	61

It was observed that 29 (47.5%) subjects were unmarried, followed by 28 (45.9%) who were married, while the remaining 4 (6.6%) subjects were either widowed or divorced.

Table 13: Distribution of subjects according to education

n=61

Years of schooling	Number of subjects (%)
No schooling	13 (21.3)
1-5	19 (31.1)
6-10	25 (41.0)
>10	4 (6.6)
Total	61

Table 13 shows that majority 25 (41.0%) subjects attended school for six to ten years, 19 (31.1%) completed primary school, 13 (21.3%) didn't receive any formal education, and only 4 (6.6%) attended school for more than ten years.

Table 14: Distribution of subjects according to present occupation n=61

Occupation	Number of subjects (%)
Labour	8 (13.1)
Agriculture	3 (4.9)
Business	3 (4.9)
Service	1 (1.6)
Student	11 (18.0)
Household work	17 (27.9)
Unemployed	18 (29.6)
Total	61

This table shows that out of 61 subjects, 8 (13.1%) were working as labourers. The number of subjects involved in agriculture and business was same, i.e., 3 (4.9%) each, and 1 (1.6%) was in service. There were 11 (18.0%) students. Among females, 17 (27.9%) were doing household work. The remaining 18 (29.6%) were unemployed.

Table 15: Status of unemployed subjects **n=18**

Reason for unemployment	Number of subjects (%)
Never worked	9 (50.0)
Left job due to epilepsy	9 (50.0)
Total	18

Out of 18 unemployed subjects, 9 (50.0%) had never worked in their lives. Among the remaining 9 (50.0%) subjects, 7 had left their job voluntarily due to epilepsy and 2 had been asked to leave employment by their employer due to the same.

Table 16: Distribution of subjects according to type of family

n=61

Type of family	Number of subjects (%)
Nuclear	30 (49.2)
Joint	31 (50.8)
Total	61

Table 16 shows that 31 (50.8%) of the subjects belonged to joint families while 49.2% to nuclear families.

Table 17: Distribution of subjects according to socio-economic status n=61

Socio economic status*		Number of subjects (%)
Score	**Class**	
>43	Upper class	-
33-42	Upper-Middle class	3 (4.9)
24-32	Middle class	17 (27.9)
13-23	Lower middle class	41 (67.2)
<13	Lower class	-
Total		61

*Classification *as per Modified Udai-Pareek socio-economic status scale*

The above table shows, 41 (67.2%) of subjects were classified as lower-middle class, 17 (27.9%) as middle class, and 3 (4.9% as upper-middle class. However, nil subject belonged to Upper and Lower class.

Table 18: Distribution of subjects as per total monthly family income n=61

Total monthly family income (₹)	Number of subjects (%)
<5000	6 (9.8)
5000-9999	25 (41.0)
10000-14999	13 (21.3)
15000-19999	6 (9.8)
≥20000	11 (18.1)
Total	61
Mean income ±SD	₹ 13500 ± 2121.32

This table shows that the total monthly family income of 6 (9.8%) subjects was less than ₹ 5000, 25 (41.0%) had income between ₹ 5000-9999, 13 (21.3%) between ₹ 10000-14999, 6 (9.8%) between ₹ 15000-19999 and 11 (18.1%) had ₹ ≥ 20000. The mean income was ₹ 13500 ± 2121.32.

Table 19: Distribution of subjects according to ethnicity n=61

Ethnicity	Number of subjects (%)
Punjabi	60 (98.4)
Migrant	1 (1.6)
Total	61

Table 19 shows that almost all of the study subjects were Punjabi, i.e., 60 (98.4%), except one, who was a migrant from Uttar Pradesh.

Figure 3: Distribution of subjects according to treatment gap

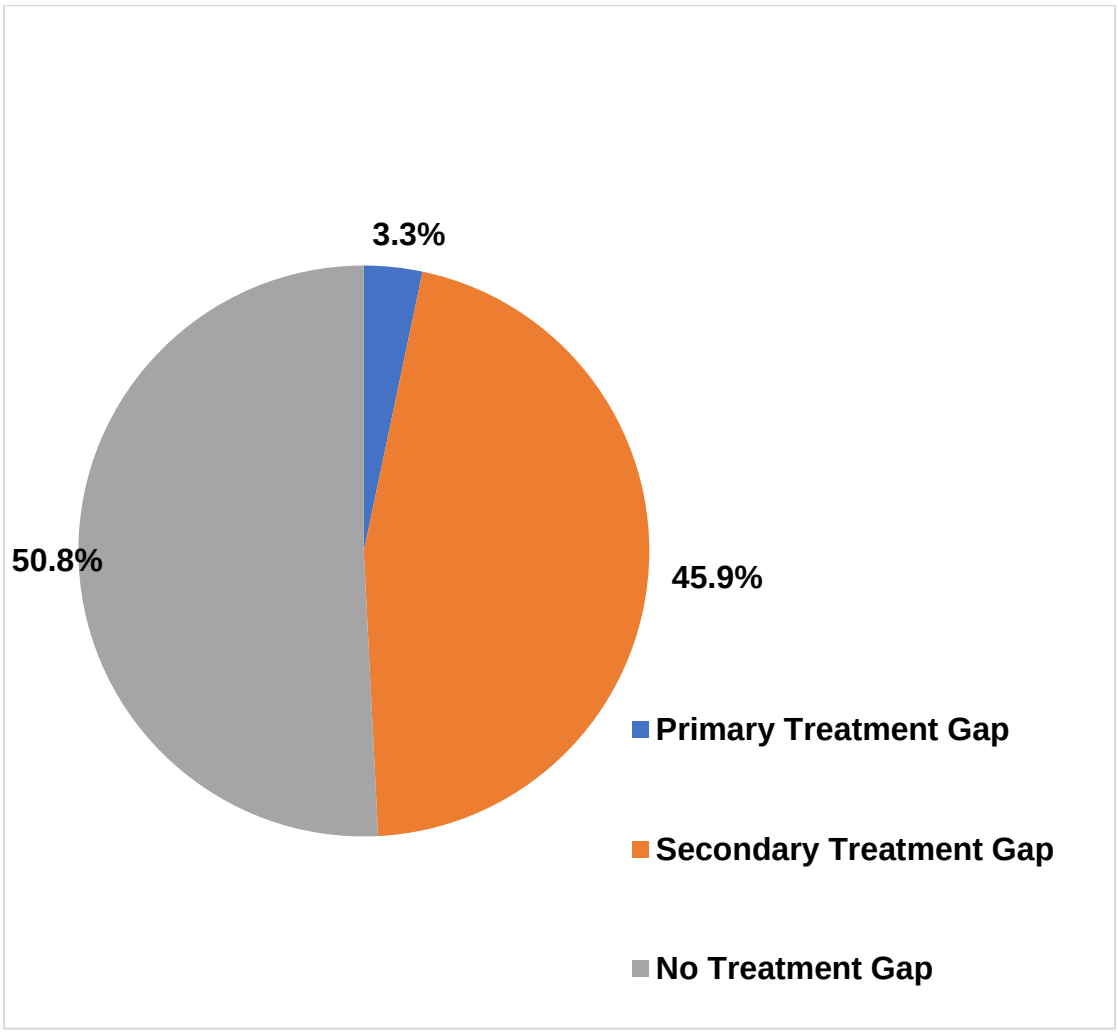


Table 20: Distribution of subjects according to treatment gap

n=61

Treatment gap		**Number of subjects (%)**
Yes	Primary [a]	2 (3.3)
	Secondary [b]	28 (45.9)
No		31 (50.8)

A treatment gap was observed in 30 (49.2%) study subjects out of total 61 subjects in the present study. The primary and secondary treatment gap was seen in 2 (3.3%) and 28 (45.9%) of the subjects, respectively.

[a] Primary treatment gap is also known as the diagnostic gap. It has been defined as people with epilepsy (PWE) who have never been diagnosed as epileptic according to internationally recommended guidelines by allopathic doctors.[47]

[b] Secondary treatment gap is also known as the therapeutic gap. It has been defined as a PWE who after diagnosis has either altogether stopped taking anti-epileptic drug or is not taking appropriate treatment as per recommended guidelines of drug of choice, dosage, or duration.[47]

Figure 4: Association of treatment gap with age of subjects

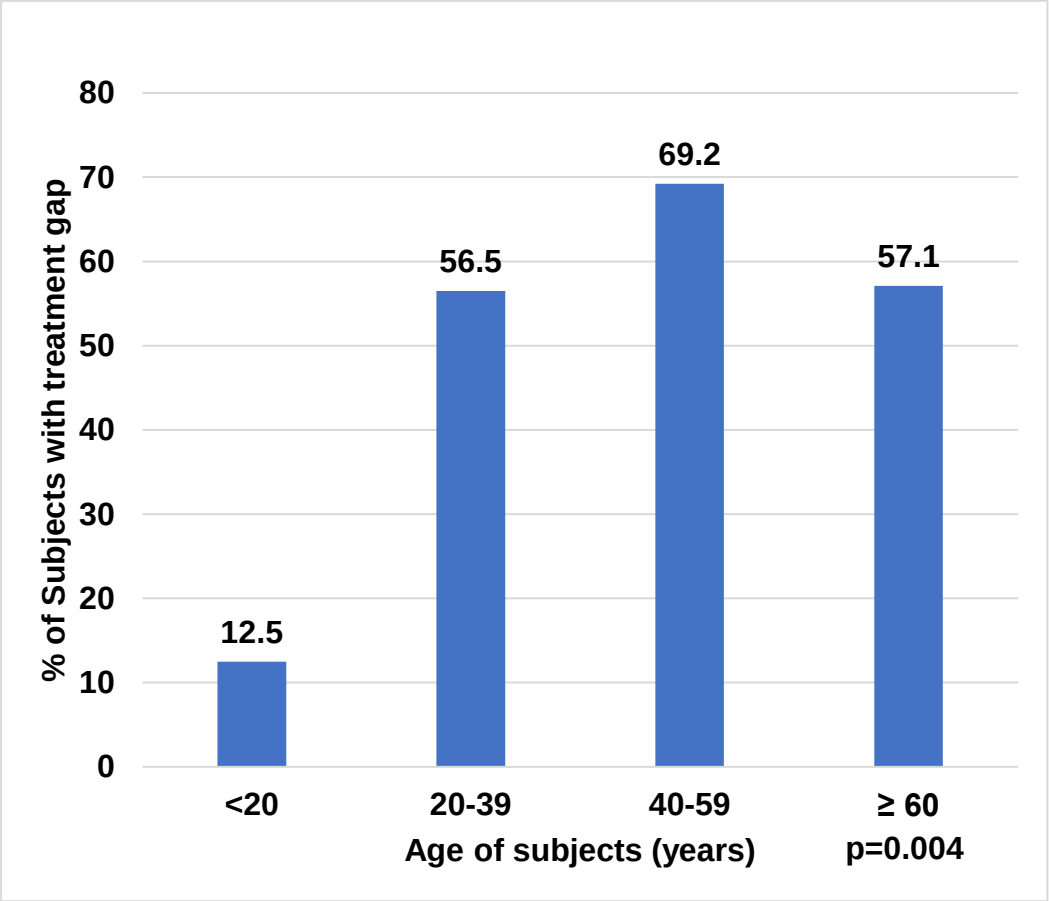


Table 21: Association of treatment gap with age of subjects

n=59*

Age (years)	Treatment gap		Total
	Yes (%)	No (%)	
<20	2 (12.5)	14 (87.5)	16
20-39	13 (56.5)	10 (43.5)	23
40-59	9 (69.2)	4 (30.8)	13
≥ 60	4 (57.1)	3 (42.9)	7
Total	28	31	59

**Two subjects never took any treatment*

Chi-square=6.904, df=1, p=0.004, Significant

The treatment gap was found to be 12.5% in age less than 20 years. It increased to 56.5%, 69.2% and 57.1% among 20–39 year, 40-59 year, and ≥60 year age groups, respectively. To find the association <20 and ≥60 year old were combined to form a dependent age group and 20-39 and 40-59 were combined to form an independent age group. The association between the treatment gap and age was statistically significant.

Table 22: Association between treatment gap and gender of subjects n=59

Gender	Treatment gap		Total
	Yes (%)	No (%)	
Male	14 (41.1)	20 (58.9)	34
Female	14 (56.0)	11 (44.0)	25
Total	28	31	59

Chi-square=1.27, df=1, p=0.134 Non-significant

In the present study, out of a total of 34 males and 25 females, a treatment gap was seen in 14 (41.1%) males and 14 (56.0%) females. The association between the treatment gap and gender was statistically non-significant.

Table 23: Association between treatment gap and religion of subjects n=59

Religion	Treatment gap		Total
	Yes (%)	No (%)	
Sikh	26 (48.2)	28 (51.8)	54
Others	2 (40.0)	3 (60.0)	5
Total	28	31	59

Fisher exact test; p=0.549, Non-significant

The treatment gap was found in 26 (48.2%) subjects belonging to the Sikh religion and 2 (40.0%) subjects of other religions. Among other religions, 1 subject belonged to Hindu and 1 subject to the Muslim religion. The association between the treatment gap and religion was statistically non-significant.

Table 24: Association between treatment gap and education status of subjects n=59

Years of schooling	Treatment gap		Total
	Yes (%)	No (%)	
No schooling	7 (58.3)	5 (40.7)	12
1-5	8 (44.4)	10 (55.6)	18
6-10	12 (48.0)	13 (52.0)	25
>10	1 (25.0)	3 (75.0)	4
Total	28	31	59

Chi square=0.715, df=2, p=0.699, Non-significant

The treatment gap was found to be 58.3% among subjects with no schooling and almost similar 44.4% and 48.0% among subjects with primary education and up to 10 years of schooling, respectively. It decreased to 25.0% among subjects who had more than 10 years of schooling. For analysis purpose, 6-10 years of schooling and >10 years of schooling was combined and three categories were formed. The association between the treatment gap and years of schooling was statistically non-significant.

Figure 5: Association between treatment gap and marital status of subjects

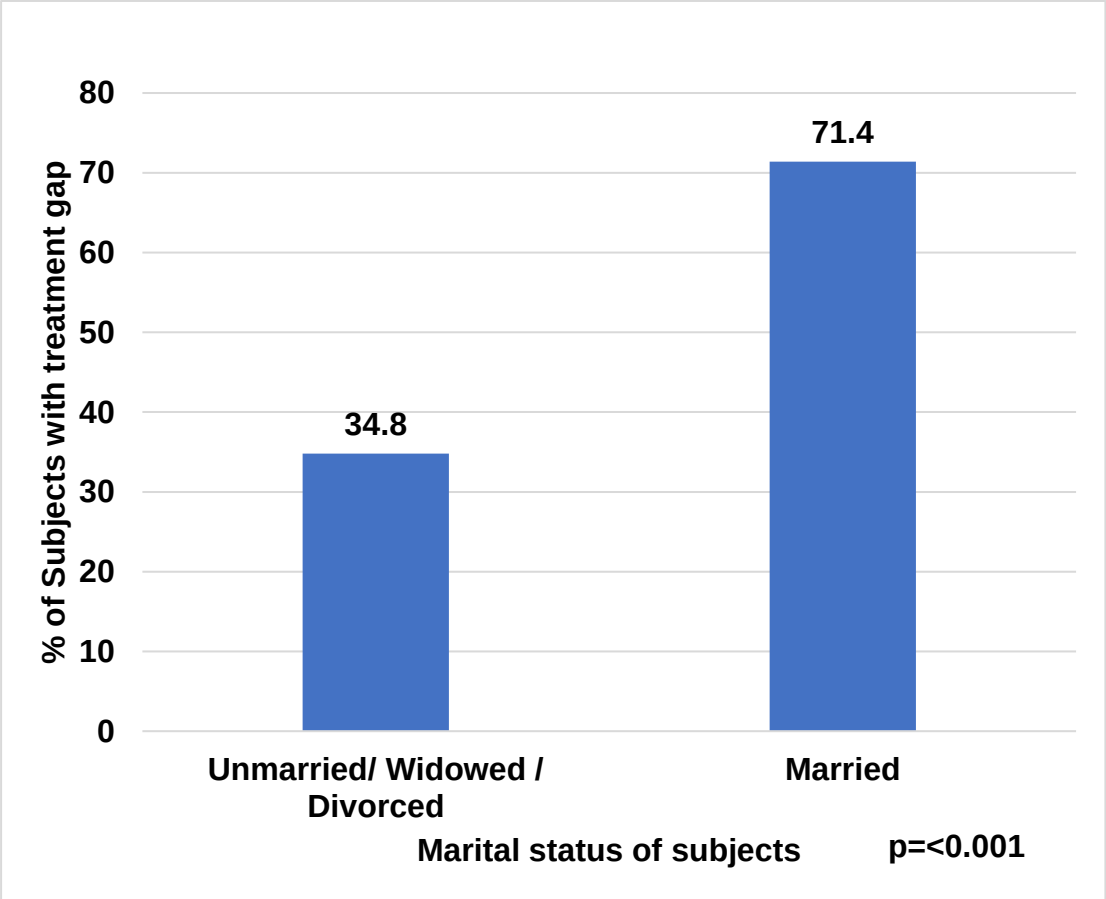


Table 25: Association between treatment gap and marital status of subjects n=59

Marital status	Treatment gap		Total
	Yes (%)	No (%)	
Unmarried/ Widowed / Divorced	8 (25.8)	23 (74.2)	31
Married	20 (71.4)	8 (28.6)	28
Total	28	31	59

Chi-square=12.28, df=1, p=<0.001, Significant

It was observed that the treatment gap was higher (71.4%) among married people living with their spouses in comparison to unmarried, widowed, and divorced (25.8%) subjects. The association between the treatment gap and marital status was statistically significant.

Table 26: Association of treatment gap with type of family of subjects n=59

Type of family	Treatment gap		Total
	Yes (%)	No (%)	
Nuclear	14 (46.6)	16 (53.4)	30
Joint	14 (48.3)	15 (51.7)	29
Total	28	31	59

Chi-square=0.015, df=1, p=0.451, Non-significant

The treatment gap was observed in 14 (46.6%) subjects out of 30 residing in nuclear families and 14 (48.3%) subjects out of 31 from joint families. The association between treatment gap and type of family was statistically non-significant.

Table 27: Association between treatment gap and socio-economic status of subjects n=59

Socio-economic class	Treatment gap		Total
	Yes (%)	No (%)	
Upper class	-	-	-
Upper-Middle class	3	-	3
Middle class	4 (21.1)	15 (78.9)	19
Lower middle class	21 (56.8)	16 (43.2)	37
Lower class	-	-	-
Total	28	31	59

Chi-square=3.441, df=1, p=0.032, Significant

Table 27 shows the association between the treatment gap and socio-economic status. For analysis purposes, the three categories were combined to form two main categories, i.e., 'upper-middle and middle class' and 'lower-middle class'. It was found that 21 (56.8%) subjects from lower middle class and 7 (31.8%) subjects from the middle and lower-middle class had treatment gap. The association between treatment gap and socio-economic status was statistically significant.

Figure 6: Association between treatment gap and current seizure frequency of subjects

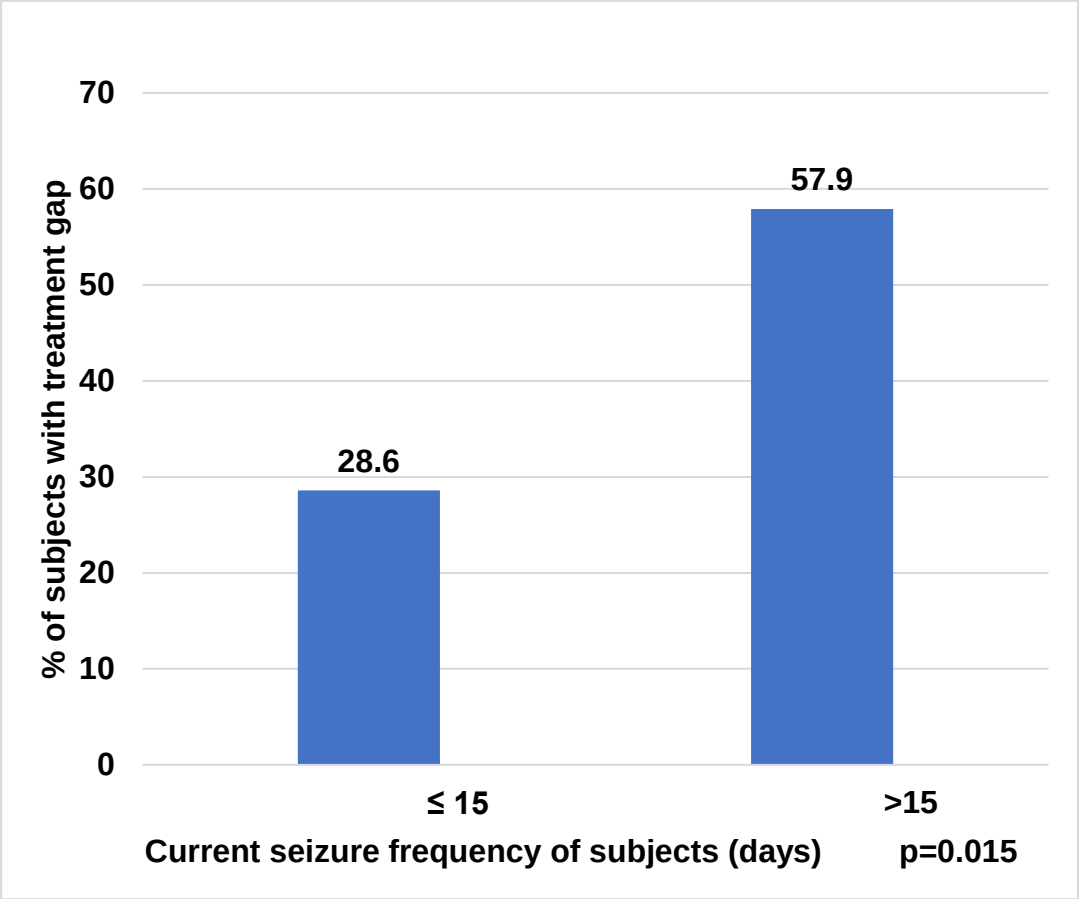


Table 28: Association between treatment gap and current seizure frequency of subjects n=59

Current seizure frequency (days)	Treatment gap		Total
	Yes (%)	No (%)	
≤ 15	6 (28.6)	15 (71.4)	21
>15	22 (57.9)	16 (42.1)	38
Total	28	31	59

Chi-square=4.664, df=1, p=0.015, Significant

Table 28 shows that the treatment gap was seen in 6 (28.6%) subjects who had seizures within 15 days of their previous seizure and in 22 (57.9%) subjects who had seizures more than 15 days after their previous seizure. The association between the treatment gap and seizure frequency was statistically significant.

Table 29: Association between treatment gap and duration since first seizure n=59

Duration since first seizure	Treatment gap		Total
	Yes (%)	No (%)	
< 5 years	7 (35.0)	13 (65.0)	20
5-9	7 (58.3)	5 (41.7)	12
≥10 years	14 (51.8)	13 (48.2)	27
Total	28	31	59

Chi square=2.023, df=2, p=0.364, Non-significant

In subjects who had suffered their first seizure less than 5 years ago, a 35.0% treatment gap was seen, and after 5 years, the treatment gap was more than 50.0%. The association between treatment gap and duration since the first seizure was statistically non-significant.

Figure 7: Association between treatment gap and type of treatment sought after first seizure among subjects

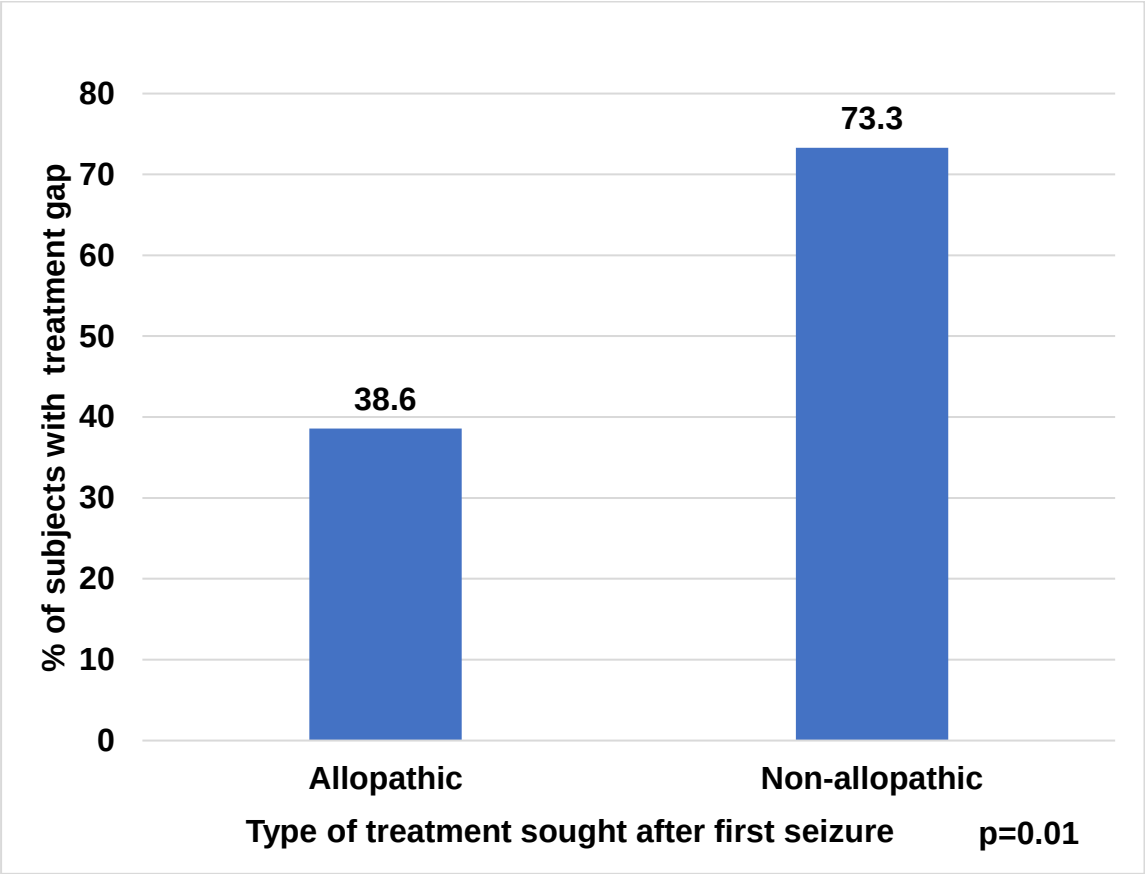


Table 30: Association between treatment gap and type of treatment sought after first seizure among subjects n=59

Type of treatment	Treatment gap		Total
	Yes (%)	No (%)	
Allopathic	17 (38.6)	27 (61.4)	44
Non-allopathic	11 (73.3)	4 (26.7)	15
Total	28	31	59

Chi-square=5.401, df=1, p=0.01, Significant

Table 30 reveals that the subjects who sought non-allopathic therapy at the time of first seizure had a 73.3 % treatment gap whereas those subjects who chose allopathic treatment after first seizure 38.6% treatment gap was found. The association between the treatment gap and type of treatment sought after the first seizure was statistically significant.

Figure 8: Association between treatment gap and time when treatment was sought after first seizure among subjects

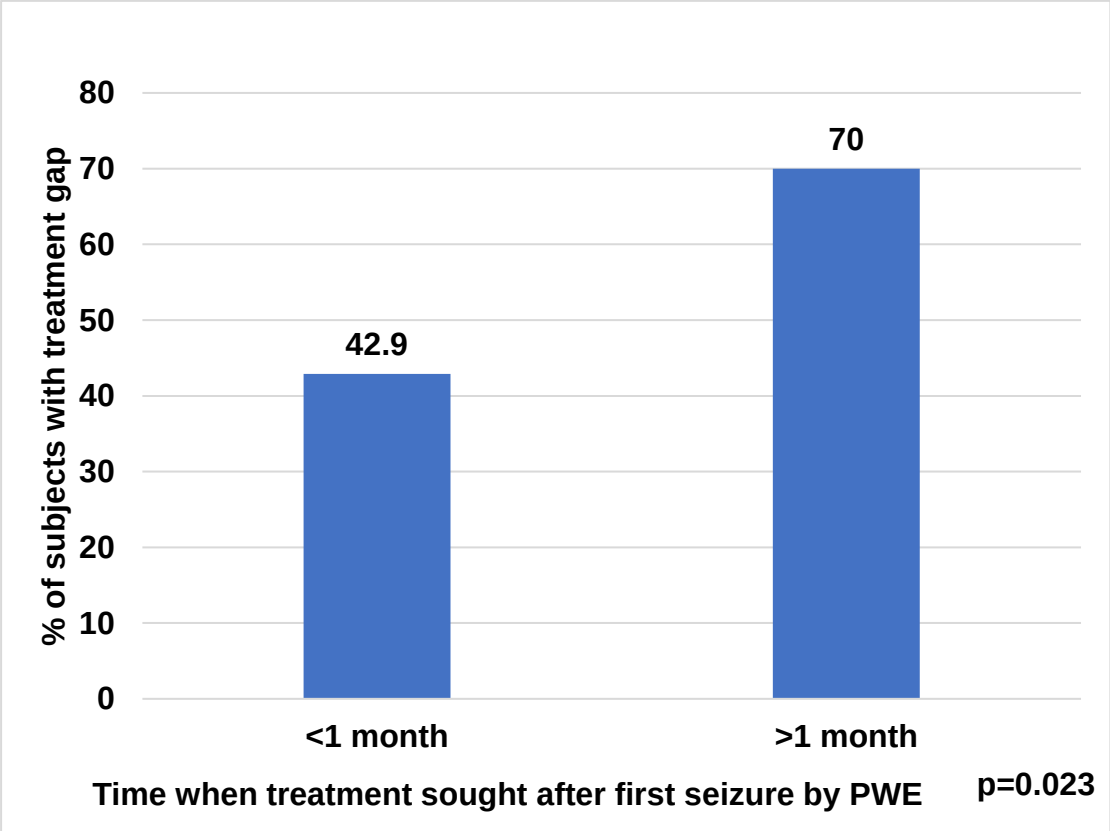


Table 31: Association between treatment gap and time when treatment was sought after first seizure among subjects n=59

Time when treatment sought after the first seizure	Treatment gap		Total
	Yes (%)	No (%)	
<1 month	21 (42.9)	28 (53.1)	49
>1 month	7 (70.0)	3 (30.0)	10
Total	28	31	59

Chi-square=3.985, df=1, p=0.023, Significant

A 42.9% treatment gap was found in subjects who had started treatment with anti-epileptic drugs (AED) within one month of suffering their first seizure, while a 70.0% treatment gap was found in those who started treatment more than one month after the first seizure. The association between the treatment gap and the time when treatment was sought after the first seizure was statistically significant.

Table 32: Association between treatment gap and number of medicines prescribed among subjects n=59

Number of AEDs prescribed	Treatment gap		Total
	Yes (%)	No (%)	
Monotherapy	14 (50.0)	14 (50.0)	28
Polytherapy	14 (45.2)	17 (54.8)	31
Total	28	31	59

Chi-square=0.0138, df=1, p=0.355, Non-significant

Table 32 shows that the treatment gap among subjects on monotherapy was 50.0% and subjects on polytherapy was <50.0%. The association between the treatment gap and the number of anti-epileptic drugs (AED) prescribed was statistically non-significant.

Table 33: Association between treatment gap and frequency of daily Anti-Epileptic Drug (AED) among subjects n=59

Frequency of daily AED	Treatment gap		Total
	Yes (%)	No (%)	
Once	8 (66.7)	4 (33.3)	12
≥Twice	20 (42.6)	27 (57.4)	47
Total	28	31	59

Chi-square=2.229, df=1, p=0.068, Non-significant

The above table shows that the treatment gap exists among two-thirds of subjects (66.7%) who take anti-epileptic drugs once a day and two-fifths of subjects (42.6%) who take them two times a day or more. The association between the treatment gap and the frequency of daily anti-epileptic drugs (AED) prescribed was statistically non-significant.

Table 34: Association between treatment gap and availability of Anti-epileptic drug (AED) among subjects n=59

Uninterrupted/ Continuous availability of AED	Treatment gap		Total
	Yes (%)	No (%)	
Yes	26 (47.3)	29 (52.7)	55
No	2 (50.0)	2 (50.0)	4
Total	28	31	59

Fischer exact: p=0.654, Non-significant

The above table shows the association between the treatment gap and AED availability. The treatment gap was 47.3% for those subjects who had continuous availability to anti-epileptic drugs and 50.0% for those who didn't. The association between treatment gap and the availability of AED was statistically non-significant.

Table 35: Association between treatment gap and duration for which AEDs was dispensed among subjects n=59

Duration (days)	Treatment gap		Total
	Yes (%)	No (%)	
≤15	18 (60.0)	12 (40.0)	30
>15	10 (34.5)	19 (65.5)	29
Total	28	31	59

Chi-square=3.851, df=1, p=0.025, Significant

It was observed that the proportion of subjects getting AEDs dispensed for ≤15 days and >15 was almost equal. The treatment gap was seen in 18 (60.0%) subjects who were being dispensed or received AEDs for ≤15 days while it was seen in 10 (34.5%) subjects who were being dispensed or received AEDs for >15 days. The association between the treatment gap and the duration for which AEDs were dispensed was statistically significant.

Figure 9: Association between treatment gap and duration for which AED was dispensed among subjects

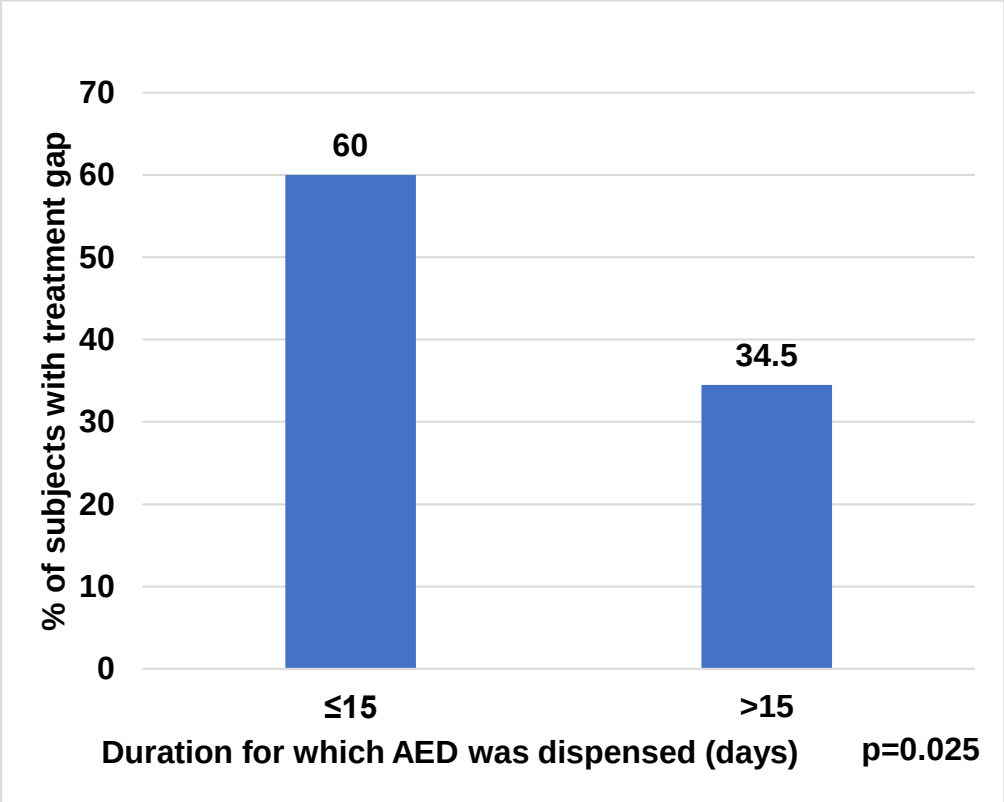


Table 36: Association between treatment gap and self-reported waiting time at hospital among subjects n=59

Waiting time (hour)	Treatment gap		Total
	Yes (%)	No (%)	
<1	6 (37.5)	10 (62.5)	16
≥1	22 (51.2)	21 (48.8)	43
Total	28	31	59

Chi-square=0.873, df=1, p=0.175, Non-significant

Table 36 shows that treatment gap was observed in 6 (37.5%) and 22 (51.2%) subjects in relation to <1 hour and ≥1 hour of self-reported waiting period at the hospital, respectively. The association between the treatment gap and the duration of the waiting period at the hospital was statistically non-significant.

Figure 10: Association between treatment gap and counselling of subjects for treatment compliance

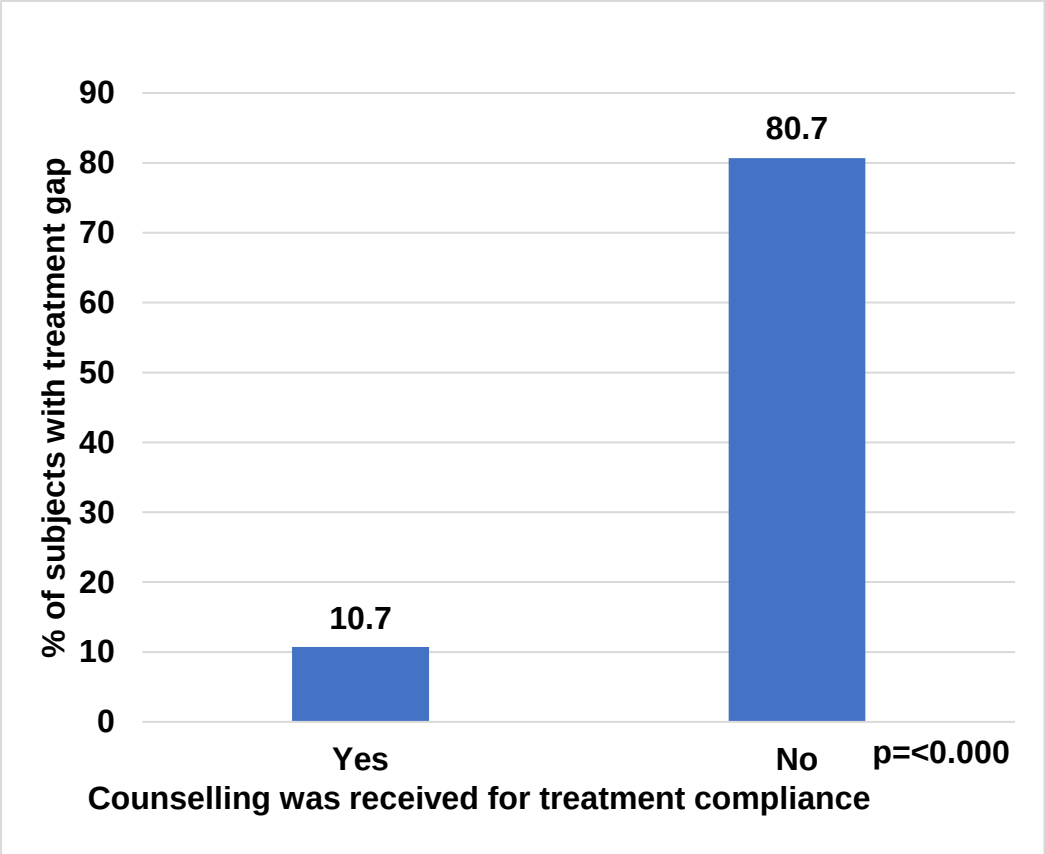


Table 37: Association between treatment gap and counselling of subjects for treatment compliance n=59

Counselling done	Treatment gap		Total
	Yes (%)	No (%)	
Yes	3 (10.7)	25 (89.3)	28
No	25 (80.6)	6 (19.4)	31
Total	28	31	59

Chi-square=28.85, df=1, p=<0.000, Significant

In the present study, 28 subjects reported that they were counselled by health care professionals and among them, 25 (89.3%) subjects were not having a treatment gap. However, 31 subjects reported that they had not received any counselling, among them 25 (80.6%) subjects had a treatment gap. The association between the treatment gap and counselling was statistically significant.

Table 38: Association of treatment gap with distance between home of subject to health facility n=59

Distance (Kilometre)	Treatment gap		Total
	Yes (%)	No (%)	
≤5	9 (47.4)	10 (52.6)	19
6-10	5 (50.0)	5 (50.0)	10
≥11	14 (46.7)	16 (53.3)	30
Total	28	31	59

Chi-square=0.034, df=2, p=0.983, Non-significant

The treatment gap was found in 9 (47.4%) subjects residing within 5 km of the health facility, followed by 5 (50.0%) and 14 (46.7%) of subjects residing within 6-10 km and more than 10 km of the health facility, respectively. The association between the treatment gap and distance from home to the health facility was statistically non-significant.

Table 39: Association between treatment gap and mode of transport used among subjects n=59

Mode of transport	Treatment gap		Total
	Yes (%)	No (%)	
Personal vehicle	23 (54.8)	19 (45.2)	42
Public transport	6 (42.9)	8 (57.1)	14
By foot	-	6	6
Total	29	33	62*

**Total exceeds n due to multiple responses*

Chi-square=3.337, df=1, p=0.034, Significant

Table 39 shows the association between the treatment gap and the mode of transport to a health facility. For analysis purposes, the three categories were merged to form two categories i.e 'personal vehicle group', and 'public transport and by foot group'. A treatment gap was found in 23 subjects who travelled by personal vehicle (54.8%) and 6 subjects who travelled by public transport (42.9%). The association between the treatment gap and the mode of transport was statistically significant.

Figure 11: Association between treatment gap and mode of transport used among subjects

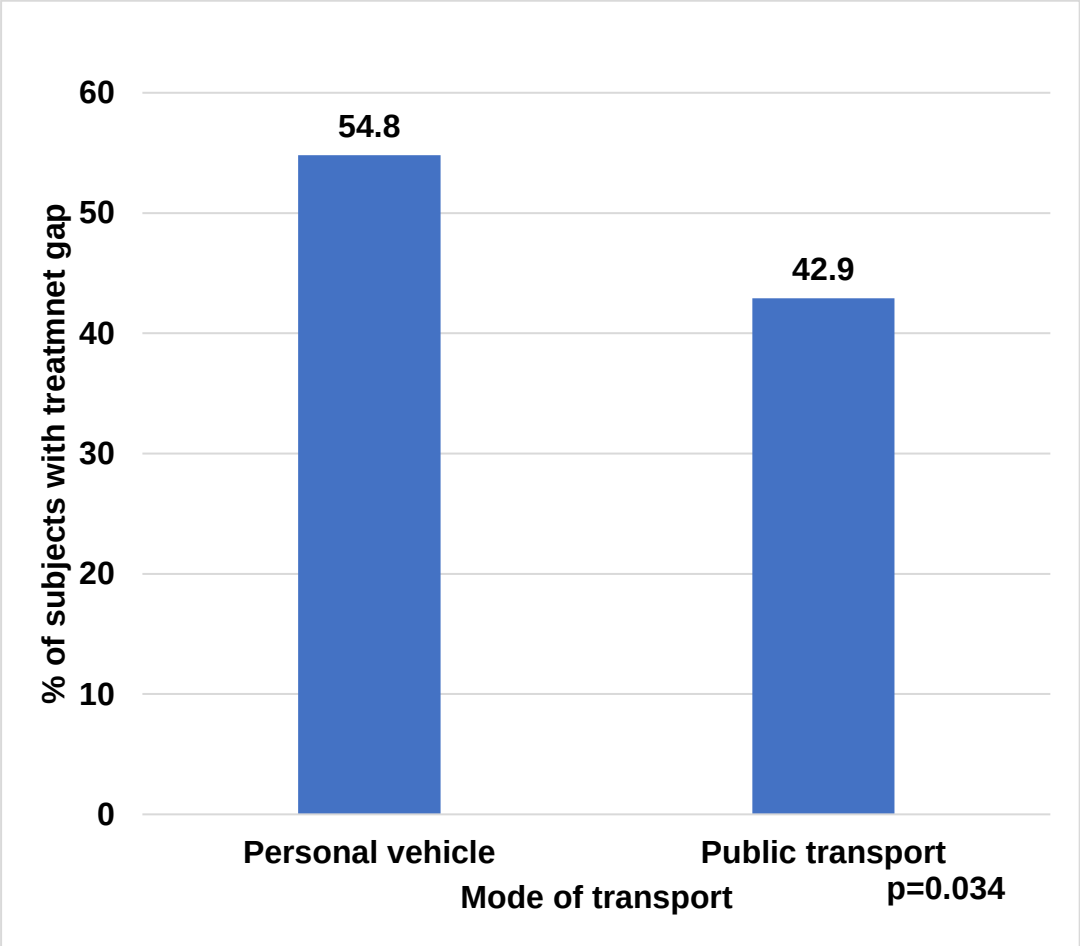


Table 40: Association between treatment gap and health insurance coverage among subjects n=59

Health Insurance	Treatment gap		Total
	Yes (%)	No (%)	
Yes	4 (30.8)	9 (69.2)	13
No	24 (52.2)	22 (47.8)	46
Total	28	31	59

Chi square=1.862, df=1, p=0.086, Non-significant

Out of 59 subjects, 13 had health insurance coverage. The treatment gap was seen in 4 (30.8%) subjects with insurance and 24 (52.2%) subjects without health insurance. The association between the treatment gap and health insurance coverage was statistically non-significant. None of the subjects had availed benefits of health insurance.

Table 41: Association between treatment gap and comorbidities among subjects n=59

Comorbidity	Treatment gap		Total
	Yes (%)	No (%)	
Yes	8 (53.3)	7 (46.7)	15
No	20 (45.5)	24 (54.5)	44
Total	28	31	59

Chi-square=0.279, df=1, p=0.299, Non-Significant

A treatment gap was observed in 8 (53.3%) comorbid subjects and 20 (45.5%) subjects who didn't have any comorbidity. The association between the treatment gap and the presence of co-morbidity was statistically non-significant.

Table 42: Association between treatment gap and family history of epilepsy among subjects n=59

Family history	Treatment gap		Total
	Yes (%)	No (%)	
Yes	3 (33.3)	6 (66.7)	9
No	25 (50.0)	25 (50.0)	50
Total	28	31	59

Fisher exact: p=0.290, Non-significant

It was found in the study that 9 subjects out of 59 had a positive family history of epilepsy. Of those, the treatment gap was observed in 3 (33.3%) subjects, whereas among subjects who didn't have a positive family history of epilepsy, there were 25 (50.0%) subjects with treatment gap. The association between the treatment gap and the family history was statistically non-significant.

Figure 12: Association between treatment gap and substance use among subjects

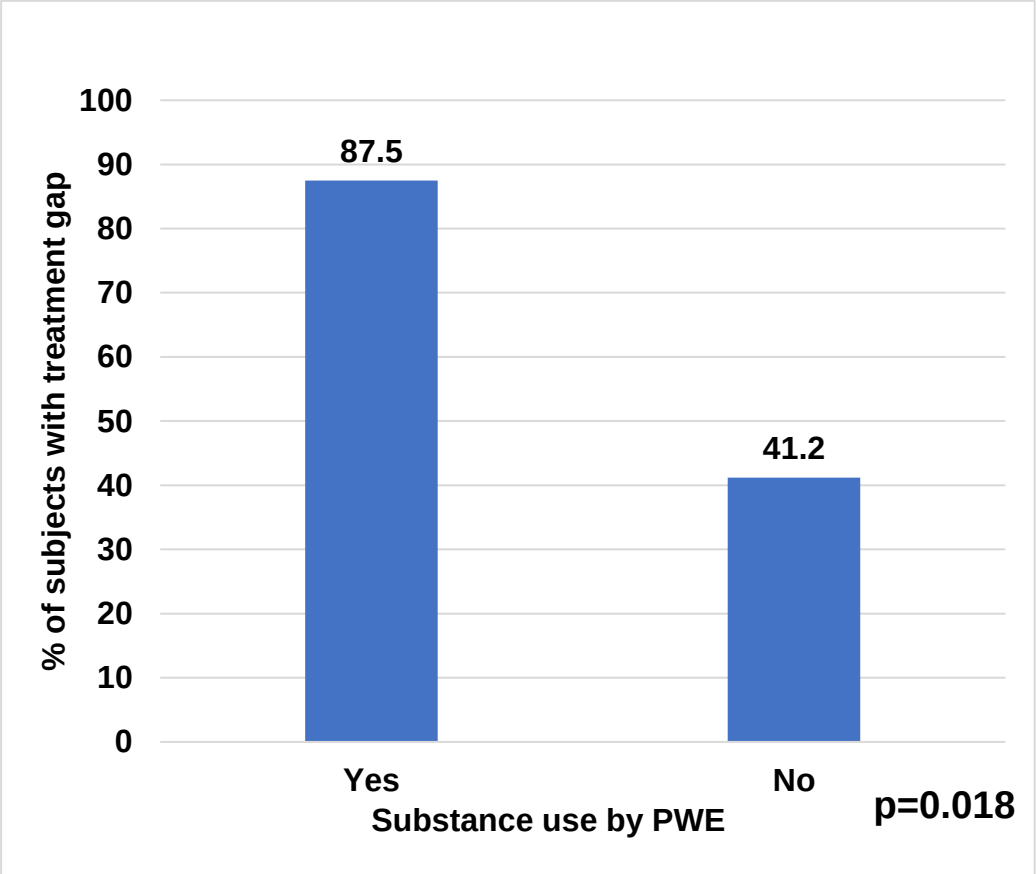


Table 43: Association between treatment gap and substance use among subjects n=59

Substance use	Treatment gap		Total
	Yes (%)	No (%)	
Yes	7 (84.5)	1 (12.5)	8
No	21 (41.2)	30 (58.8)	51
Total	28	31	59

Fisher exact: p=0.018, Significant

In the present study, out of 59 only 8 subjects gave history of substance use (alcohol, tobacco, opium) and all of them were male. A treatment gap was observed in 7 (84.5%) subjects with substance use and 21 (41.2%) subjects without substance use. The association between the treatment gap and substance use was statistically significant.

Table 44: Reason for non-compliance / non-adherence with AED amongst subjects with treatment gap

Reason for non-compliance/ non-adherence	No of subjects
Forgot to take AED	15
Could not afford to buy AED	1
Tried but could not find a place to buy AED	1
Didn't want to buy AED	1
Were seizure-free	4
Seizures were not under control despite AED	3
Having side effects with AED	6
Got fed up with taking medicine	6
To check if any problem will occur from decreasing dose from thrice to twice daily	1
Didn't have means of transport to go and get AED	2
Didn't want to travel	1
Didn't have time to get AED	4
Had to go to work	2
Had household work	5
The family is not supportive	3
Didn't like the attitude of the healthcare provider	1

**Total exceeds n due to multiple responses*

Table 44 enumerates the various reasons quoted by PWE for non-compliance / non-adherence. Forgetfulness was the most common followed by having adverse effects with anti-epileptic drugs and frustration with taking medicine.

Table 45: Distribution of subjects as per their knowledge and beliefs regarding epilepsy.

Knowledge and beliefs		Yes (%)
Knowledge	Heard about epilepsy before their diagnosis (n=59)	18 (30.5)
	Don't know the cause of epilepsy (n=61)	36 (59.0)
	Epilepsy is a brain disorder (n=61)	21 (34.4)
Beliefs	Do you think prescribed AED will cure epilepsy? (n=54)	46 (85.2)
	Epilepsy is caused by God's curse (n=61)	2 (3.3)
	Epilepsy is caused by Karma (n=61)	12 (19.7)
	Epilepsy is caused by reflection from water/ mirror (n=61)	7 (11.5)

Knowledge and beliefs of subjects and their caregivers are one of the major determinants of the epilepsy treatment gap. In this study, 30.5% had heard about epilepsy before and 34.4% knew it was a brain disorder. However, 59.0% didn't know the cause of epilepsy. The PWE who believed that the prescribed AED would cure their epilepsy were 85.2% and 34.5% believed epilepsy was caused by God's curse, karma, or reflection from water or mirror.

DISCUSSION

The present study “Prevalence of epilepsy and Determinants of treatment gap in People with epilepsy in rural Ludhiana” is a community-based cross-sectional study. The study has been carried out in the field practice area of the Rural Health Training Center (RHTC) located at Village Pohir, Block Dehlon, District Ludhiana, Punjab, India. The RHTC Pohir is an integral part of the Department of Community Medicine, Dayanand Medical College and Hospital, Ludhiana.

The field practice area comprises of fifteen villages where home-based comprehensive health care is provided. It covers a population of 31043 as per the quarterly report of RHTC Pohir, June 30th, 2019.

The whole population of 31043 was screened with Placencia’s 9-item screening questionnaire by door-to-door visit. A total of 195 persons were found to be screened positive on the administration of the screening questionnaire.

Out of 195 screen positive individuals, 4 died before clinical evaluation, 4 refused to participate in the study, and the remaining 187 were clinically and/or diagnostically evaluated by the neurological team. These screen positive persons were classified as having active epilepsy (n=61), inactive epilepsy (n=17), acute symptomatic seizure, single seizure, psychological non-epileptic seizure, diagnosis not determined, and other diagnosis by the neurologist.

The number of subjects diagnosed as having active or inactive epilepsy was used to calculate the lifetime prevalence of epilepsy. Whereas the number of subjects with active epilepsy was used to calculate the prevalence of epilepsy, and they were further studied for the determinants of the treatment gap.

POPULATION AND SAMPLE CHARACTERISTICS

According to the 2011 census, 68.9% of the population of India resides in rural area.[61] As per the statistical abstract of Punjab

(2020), 62.5% of the residents of Punjab and 40.8% of the Ludhiana population live in the rural areas. This can be due to Ludhiana being an industrial city.[62]

AGE

In the present study, 25% of the population was <20 years of age, 61.2% was in the 20-59 year age group, and the remaining 13.8% was >60 years of age. The study population's mean age was 54.5 ± 13.4 year. (Table 1)

As per census 2011, 34.6% of the population of rural Ludhiana was under the age of 20, 53.9% in 20–59 year age group, and the remaining 11.5% were over the age of 60 years.[61]

The difference can be attributed to the fact that the population has aged by 10 years since the previous census. Therefore, the 10% decline in <20 year age group can be seen as a 10% increase in 20–59 year age group.

GENDER

In the present study, the males and females were found to be 53.0% and 47.0%, respectively, of the total study population. (Table 2) This corresponds to the statistical abstract of Punjab (2020), as there were 52.4% of males and 47.6% of females in rural Punjab. The Census (2011) reveals that the males and females were 52.7% and 47.3%, respectively, in the fifteen villages that were part of the current study.[61,62]

AGE AND GENDER

Age and gender are important determinants in any health condition. At the extremes of age, young and old, individuals are dependent on their family members for financial stability. It was seen that more than half of the study population, i.e.,61.1% of males and 61.2% of females, are in the age group of 20-59 years. (Table 3)

Similar age and gender-wise distribution was reported in the 2011 Ludhiana census, which revealed that more than half of the males (52.8%) and females (55.0%) were in the age group of 20-59 years.[61]

SCREENING FOR EPILEPSY

Placencia's 9-item screening tool was administered to a total study population of 31043, out of which 195 (0.6%) were found to have suspected epilepsy. (Table 4)

Panagariya *et al* (2018) employed the same screening tool in their study "Prevalence, demographic profile, and psychological aspects of epilepsy in north-western India: A community-based observational study" and covered the population in both rural and urban Jaipur. Out of a 3,44,802 study population, 450 (0.13%) were screened as positive individuals. The difference observed may be due to the social stigma prevalent in the area concerning epilepsy.[11]

CLASSIFICATION OF SCREEN POSITIVE PERSONS

In the present study, out of 195 screened positive individuals, four refused to participate in the study and four died before clinical evaluation. The remaining 187 were clinically and/or diagnostically evaluated by the neurology team of the institute.

The screened positive individuals were characterized according to ILAE recommendations and 61 (32.6%) persons had active epilepsy, 17 (9.1%) inactive epilepsy, 28 (15.0%) acute symptomatic seizure, 12 (6.4%) single seizure, and 5 (2.7%) psychogenic non-epileptic seizure. The diagnosis of 7 (3.7%) of them was indeterminate, whereas 57 (30.5%) of them had other diagnoses. (Table 5)

In contrast to these findings, Panagariya *et al* (2018) showed that 380 (84.4%) persons were diagnosed as active epilepsy cases out of 450 screen positive persons using the same ILAE recommended guidelines for epidemiological studies of epilepsy. Out of these 380, 304 and 76 were in rural and urban Jaipur, respectively.[11]

This variation can be attributed to the fact that Panagariya *et al (2018)* engaged community workers who initially asked the head of the family whether anyone in their family had epilepsy, and only among suspected cases the screening tool was applied. However, in the present study, the screening tool was applied to the whole study population, which led to the detection of non-epileptic seizures and other conditions mimicking seizures.

PREVALENCE OF EPILEPSY

LIFETIME PREVALENCE OF EPILEPSY

In the present study, the lifetime prevalence of epilepsy was found to be 2.5 per 1,000 study population. It includes individuals who have developed epilepsy at some point during their lifetime. (Table 6)

Mac *et al* (2007) conducted "Epidemiology, aetiology, and clinical management of epilepsy in Asia: a systematic review" and reported a lifetime prevalence of epilepsy of 1.5 to 14.0 per 1,000, which varied among Asian countries.[63] In contrast, Hara *et al* (2008) conducted "Epilepsy in Punjab (India): a population-based epidemiological study" in rural Patiala. A lifetime prevalence of 9.1 per thousand was reported. This variation was attributed to differences in methodologies and the type of questionnaire used.[12]

PREVALENCE OF ACTIVE EPILEPSY

In the present study, the prevalence of active epilepsy was found to be 1.96 per 1,000 study population. (Table 6)

Similar findings were reported by Panagariya *et al* (2018) in rural Jaipur. The reported prevalence of active epilepsy was 1.8 per 1,000 population.[11] Koul *et al* (1988) conducted a study in rural Kashmir and reported a prevalence of 2.47 per 1,000 in the general population.[64]

AGE-SPECIFIC LIFETIME PREVALENCE OF EPILEPSY

Epilepsy exhibits a bimodal age distribution, and its prevalence varies with every decade of life. [10]

In the present study, the age-specific lifetime prevalence of epilepsy was found to be highest at 3.4 per 1,000 persons in the age group of ≥80 years, followed by 3.1 per 1,000 persons aged 20-29 years. (Table 7)

In a study conducted by Pakdaman *et al* (2021) in Iran, the age-specific lifetime prevalence of epilepsy reported was 32.7 per 1,000 population in the 16–19 year age group, followed by 27.1 per 1,000 population in the ≥80 year age group. The high prevalence in Iran was attributed to the high proportion of traumatic events and Iran-Iraq war injuries.[65]

AGE AND GENDER-WISE DISTRIBUTION OF LIFETIME PREVALENCE OF EPILEPSY

In the present study (Table 8), it was seen that the overall age and gender-wise lifetime prevalence of epilepsy were 2.7 and 2.3 per 1,000 among males and females, respectively. The lifetime prevalence among males was in the 70–79 year age group (5.6 per 1,000), followed by the 20–29 year age group (3.8 per 1,000). Amongst females, the lifetime prevalence of epilepsy was 3.7 per 1,000 in the 30–39 year age group and ≥80 years of age group. (Table 8)

Pakdaman *et al* (2021) reported that the overall gender-specific lifetime prevalence of epilepsy is higher in males as compared to females. Amongst males, it was (45.7 per 1,000 population) in the 15–19 year age group, followed by 23.4 per thousand in the 10–14 year age group. Among females, it was 35.7 per 1,000 in the ≥80 year age group and 24.1 per 1,000 in the 0–4 year age group. The high prevalence was attributed to the high proportion of traumatic events and Iran-Iraq war injuries.[65]

AGE-SPECIFIC PREVALENCE OF ACTIVE EPILEPSY

The overall prevalence of active epilepsy was 1.96 per thousand population. The prevalence of active epilepsy ranged from 0.8 to 2.9

per 1,000 population in different age groups. The age-specific prevalence was 2.1, 1.95, and 1.85 per 1,000 in the <20 year, 20-59 years and ≥60 year of age group, respectively. (Table 9)

In contrast, Radhakrishan *et al* (2000) reported the prevalence of 5.4, 5.0, and 2.5 per 1,000 population in the < 20-year, 20-59 year, and ≥60 year age-groups, respectively, in a rural area of Kerala. This high prevalence was due to increased public compliance and case ascertainment because of the involvement of village heads and other officials.[52]

In a rural area of Kashmir, Koul *et al* (1988) observed a/the prevalence of 3.18 in the <14 year age and 1.96 per 1,000 population in >14 year age group.[64]

AGE AND GENDER-WISE PREVALENCE OF ACTIVE EPILEPSY

The overall gender-wise prevalence of active epilepsy per thousand population was slightly higher in males (2.1) as compared to females (1.9). Similar findings were reported by Zheng *et al* (2021)[66] in a study conducted in rural China with a prevalence of 2.49 per 1,000 in males and 2.17 in females. Beghi and Giussani (2020)[67] conducted a review of the epidemiology of epilepsy and reported a slightly higher prevalence of epilepsy among males than females. Mansukhani *et al* (2018)[68] conducted a study in the tribal population of Gujrat and reported that there were 3.4 and 1.7 per 1,000 males and females, respectively. Panagariya *et al* (2018)[11] reported a male-to-female ratio of 2.1:1 for the number of active epilepsy cases. This was attributed to social and cultural issues prevalent in society, which determine health-seeking behaviour among females and cause under-diagnosis of epilepsy.

In the present study, the prevalence was 5.6 in 70–79 year age group in males, followed by 2.9 per 1,000 population in <10 year age group. Amongst females, the prevalence was 3.7, 2.9, and 2.5 per 1,000 population in ≥80 year, 30-39 year, and <10 year age groups,

respectively. (Table 10) This difference in prevalence could be due to the concealment of epilepsy in females for socio-cultural reasons.

Koul *et al* (1988) reported an overall gender-wise prevalence of 2.82 and 2.07 per 1,000 among males and females, respectively. In the <14 year age group, it was 4.17 and 2.16, and in the >14 year age group, it was 1.92 and 2.01 per 1,000, male and female, respectively.[64]

CHARACTERISTICS OF SUBJECTS WITH ACTIVE EPILEPSY

RELIGION

Amongst study subjects with active epilepsy, the majority (91.8%) were Sikhs, followed by Hindus (4.9%) and Muslims (3.3%). (Table 11) Radhakrishan *et al* (2000) reported 54.0% of people with epilepsy followed the Hindu religion, 37.4% were Muslim, and 8.6% were Christian in a study conducted in Kerala.[52]

MARITAL STATUS

In the present study, 45.9% of the subjects were living with their spouses, 47.5% unmarried and 6.6% were either widowed or divorced.

EDUCATIONAL STATUS

In the present study, 21.3% of subjects were illiterate, 31.1% of subjects completed primary education and 41.0% of subjects had 6-10 years of schooling. Only 6.6% of subjects had education beyond 10 years of schooling.

Panagariya *et al* (2018)[11] reported that 44% of epilepsy cases were illiterate, 14% had primary education, 8.9% had secondary education, and 6.5% completed graduation.

A study conducted in the urban slum of Ludhiana by Singh *et al* (2012)[31] reported 9.4% of cases with epilepsy had education above matric and the remaining 90.6% had education below matric.

Radhakrishan *et al* (2000)[52] reported that 8% PWE were illiterate, 30% completed primary school, 47% in high school, 14% college, and 0.4% had professional degrees.

OCCUPATION

In the present study, 24.5% of the subjects were engaged in income-generating occupations, 28% were doing household work and 29.6% number of the subjects were unemployed. (Table 14). Among unemployed subjects, 50% hadn't worked in their lives, and the remaining 50% had to leave employment because of epilepsy, either voluntarily or because they were asked by the employer. (Table 15)

Singh *et al* (2012)[31] reported that two-fifths of cases were engaged in either business or service and three-fifths were labourers. About one-third of them were serving outside for money, and two-thirds were working at home.

Banerjee *et al* (2010)[69] conducted a longitudinal study in Kolkata and reported that in slum areas two-fifths and in non-slum areas four-fifths of PWE were engaged in income-generating occupations.

A study in Kerala was conducted by Radhakrishan *et al* (2000)[52] and reported that 63% of PWE were unemployed, 18% were labourers, 6% were students, and the remaining were either engaged in business or service.

TYPE OF FAMILY

Epilepsy is unpredictable. PWE needs physical, economic, social, and emotional support, which can be provided at an appropriate time by family members. In the present study, 50.8% of the subjects resided in joint families. (Table 16)

A study conducted by Singh *et al* (2012)[31] reported that about 15.1% of PWE were living in joint families and 84.9% were in nuclear families. This difference can be due to the difference in rural and sub-urban areas.

SOCIO-ECONOMIC STATUS

In the present study, 67.2% of the subjects belonged to the lower middle class, and 27.9% and 4.9% belonged to the middle and upper-middle classes, respectively.

Panagariya *et al* (2018)[11] reported that more than two-thirds of the subjects belonged to lower socioeconomic status and slightly less than one-third were from the middle or upper-middle class. Socio-economic status was significantly associated with the types of seizures.

Begley *et al* (2011)[70] conducted a study in New York and Houston and studied the effect of socio-economic status on the outcomes of epilepsy. PWE living in low socio-economic status sites had a greater likelihood of uncontrolled seizures.

FAMILY INCOME

PWE are directly dependent on family income for availing of diagnostic and therapeutic services. In the present study, half (50.8%) of the subjects had a family monthly income of <₹10,000 and the 49.2% had an income of ₹10,000 to 25,000. The mean monthly income was ₹13500 ± 2121.32.

A study conducted by Begley *et al* (2011)[70] in Houston and New York reported that the majority of PWE had family incomes below the federal poverty limit. Banerjee *et al* (2010)[69] reported a higher proportion of epilepsy among PWE with an income of between ₹2,000 and 3,000, both from slum and non-slum areas. A review study by Amudhan *et al* (2015)[51] in India reported lower income is also one of the risk factors for epilepsy.

ETHNICITY

World Health Organization (WHO) (2019) considered ethnicity as one of the factors affecting the prevalence of epilepsy and mortality among

PWE[10]. In the present study, almost all of the subjects belonged to Punjab; only one was a migrant from Uttar Pradesh.

TREATMENT GAP

The epilepsy treatment gap is a valuable indicator of availability, accessibility, acceptability and quality of health care services being provided for epilepsy treatment. In the present study, a primary treatment gap was seen among 2 (3.3%) subjects and a secondary treatment gap was seen in 28 (45.9%) of the subjects.

These findings are in concordance with a study done by Das *et al* (2007)[54], in Kolkata for evaluation of factors responsible for discontinuation of treatment among PWE and observed a 42.75% secondary treatment gap among PWE. Similarly, in a global systematic review, Meyer *et al* (2010)[17] had estimated that the treatment gap in rural India ranged from 40.0% to 90.0%.

These findings are in contrast to observations by Panagariya *et al* (2018)[11] who reported a primary treatment gap of 18.8% in Jaipur. The secondary treatment gap was reported in 38.0% PWE. The lower primary treatment gap in the present study can be attributed to home-based comprehensive health care provided by health workers in the study population.

However, in a study conducted in 1–18 year age group in Chandigarh, an overall treatment gap of 22% was reported by Pandey *et al* (2014)[15].

The primary treatment gap was seen in 2 subjects and both were females in the present study (Table 20). Similarly, the study “High Prevalence of epilepsy in Northern Rwanda: Exploring gender differences” conducted by Dedeken *et al* (2021)[71] reported a higher primary treatment gap in females as compared to males.

TREATMENT GAP AND AGE

The young and senior citizens are dependent on adult family members for physical and economic support. It was observed that among PWE in the age groups of 20-59, there was a higher treatment gap as compared to those less than 20 and ≥60 year age groups. The association between the two classes was found to be statistically significant. This may be because <20 and ≥60 year age groups are being taken care of by their family members, while the 20–59 year age group miss treatment to avoid loss of daily wages. (Table 21)

However, a study conducted on the epilepsy treatment gap by Wagner *et al* (2020)[72] in Ghana reported higher adherence in adults which leads to a lesser treatment gap as compared to young and aged PWE. These findings are in contrast to the findings of the present study.

TREATMENT GAP AND GENDER

In rural areas of Punjab, gender bias is prevalent right from birth, as it is evident from the Sex-ratio. Though it is improving but is still below the national level. This bias can also be seen in the health-seeking behaviour of males and females. In the present study, 56.0% females had a secondary treatment gap as compared to 41.1% male subjects. (Table 22)

Similar findings were observed by Dedeken *et al* (2021)[71] in a study conducted in Rwanda and reported that the secondary treatment gap was more amongst females with epilepsy as compared to male counterparts.

In contrast to the findings of the present study, Wagner *et al* (2020)[72] reported similar non-adherence in males (63.3%) and females (62.7%), resulting in an almost equal treatment gap in both. This could be because of different practices prevalent in the study area.

TREATMENT GAP AND RELIGION

Various religions practice a wide range of traditional remedies. But these remedies don't fulfil the criteria of appropriate treatment as recommended by various international organizations. In the present study, the treatment gap was seen in 48.2% of Sikhs and 40.0% subjects following other religions. (Table 23)

TREATMENT GAP AND EDUCATION

Education is one of the key determinants that decides how a PWE seeks appropriate treatment. Epilepsy treatment gap and education are interdependent. In the present study, 58.3% treatment gap was seen in PWE who had no formal education, and it decreased to 25% in individuals who had completed more than 10 years of schooling. (Table 24)

In contrast to the findings of the present study, Wagner *et al* (2020)[72] reported that non-adherence was higher across the spectrum of years of schooling completed, resulting in a higher treatment gap. Similarly, Mbuba *et al* (2012)[49] observed lower non-adherence amongst PWE who had no formal education and higher non-adherence amongst PWE who had completed tertiary education, leading to a lower and higher treatment gap, respectively.

TREATMENT GAP AND MARITAL STATUS

Marriage is a protective factor in chronic disease but epilepsy doesn't follow the same. In the present study, a 71.4% treatment gap was seen in married PWE and a 25.8% in unmarried, Widowed and divorced PWE. (Table 25)

The findings of the present study were in concordance with those reported by Mbuba *et al* (2012)[49] who reported a 56.8% treatment gap in married PWE as compared to a 42.0% treatment gap due to non-adherence in the single, separated, and divorced PWE. In a study conducted by Wang *et al* (2017)[73] in China, a 48.5% and 36.3%

treatment gap due to non-compliance was observed in married and unmarried PWE, respectively.

TREATMENT GAP AND TYPE OF FAMILY

In times of illness, the family provides nurturing. However, chronic illnesses like epilepsy put a financial and psychosocial burden on family members as well. In the present study, treatment gap was seen in 46.6% of PWE belonging to nuclear families and 48.3% of PWE residing in joint families. There was no significant difference between family type and the treatment gap. (Table 26)

TREATMENT GAP AND SOCIOECONOMIC STATUS

The socio-economic status of a PWE gives an overall view of various determinants of health, i.e., occupation, education, income, and family assets. In the present study, a 56.8% treatment gap was seen in the lower middle class and a 31.8% treatment gap in the middle and upper-middle classes. (Table 27)

The findings are comparable to those of Panagariya *et al* (2018)[11], who had observed a 71% treatment gap in lower socioeconomic class and in a review Amudhan *et al* (2015)[51] revealed that lower socioeconomic status was a risk factor for treatment gap.

TREATMENT GAP AND CURRENT SEIZURE FREQUENCY

One of the goals of treatment in epilepsy is to get freedom from seizures or to decrease seizure frequency which improves the quality of life. Andersen's behavioural model suggests that the lower seizure frequency is also a perceived need among PWE. Subjects who had current seizure frequency once and more than once in ≤15 days had a treatment gap of 28.6% and 57.9% in PWE who had seizure frequency of more than 15 days. (Table 28)

The findings in the present study are in concordance with that of a study conducted in rural South Africa by Wagner *et al* (2020)[72] which revealed that there was a statistically significant association between

greater seizure frequency and self-reported compliance to AED which led to lower treatment gap.

TREATMENT GAP AND DURATION SINCE FIRST SEIZURE.

In the present study, treatment gap was 50% and 35% in PWE who had their first seizure >5 years ago and <5 years ago, respectively. (Table 29)

These findings are in agreement with that of a study conducted in Kenya by Mbuba *et al* (2012)[49] in which it was observed that the duration of >10 years of epilepsy was significantly associated with non-adherence, which led to a treatment gap. However, contrast findings were revealed in a community-based study conducted in rural Tanzania by Hunter *et al* (2016)[74].

TREATMENT GAP AND TYPE OF TREATMENT SOUGHT AFTER FIRST SEIZURE

The alternative non-allopathic treatment modalities available in India are Ayurveda, Unani, Siddha, and Homeopathy. Based upon faith, previous experience, or the recommendation of a relative or friend people have their own preference for choice of the type of treatment. In the present study, PWE who sought non-allopathic treatment after their first seizure had a treatment gap of 73.3% as compared to 38.6% in PWE who sought allopathic treatment after their first seizure. (Table 30)

TREATMENT GAP AND TIME WHEN TREATMENT WAS SOUGHT AFTER THEIR FIRST SEIZURE

The first seizure requires thorough evaluation and proper counselling of PWE and their caregivers. The delay in initiation of treatment is associated with refractory epilepsy. A treatment gap of 42.9% and 70.0% were observed among PWE who sought treatment within one month and more than one month after their first seizure, respectively, in the present study. A statistically significant association was observed. (Table 31)

TREATMENT GAP AND NUMBER OF MEDICINES PRESCRIBED

The treatment gap among PWE receiving monotherapy was 50.0% and those receiving polytherapy was 45.2%. Polytherapy (more than one AED) is usually prescribed for PWE with refractory epilepsy or more frequent seizures. This may be the reason for their better compliance than PWE on monotherapy (single AED). These findings are similar to study conducted by Mbuba *et al* (2012)[49] who reported 41.1% non-adherence leading to treatment gap in PWE on polytherapy as compared to 56.9% in PWE on monotherapy. (Table 32)

However, Joseph *et al* (2013)[75] conducted a study in Karnataka and reported better compliance with monotherapy.

TREATMENT GAP AND FREQUENCY OF DAILY AED

The daily dosage depends on many factors like age, indication, duration of action of the AED prescribed, comorbidities, concomitant medication. In the present study, a treatment gap was observed in 42.6% PWE who were prescribed AED more than once daily and 66.7% treatment gap in PWE who were prescribed once-daily regimen. (Table 33)

TREATMENT GAP AND AVAILABILITY OF AED

One of the major factor to reduce the epilepsy treatment gap is to ensure the continuous availability of AED. In the present study, a treatment gap was seen in 47.3% of PWE who reported continuous availability of AED as compared to 50.0% subjects who reported interrupted availability of AED. (Table 34) The findings of the present study are in agreement with the study conducted by Singh *et al* (2020)[76] who reported that ensuring availability is one of the key factors addressing the treatment gap in epilepsy. Similarly, a systematic review conducted by Amudhan *et al* (2015)[51] has reported 18% to 44% treatment gap due to the unavailability of AED.

TREATMENT GAP AND DURATION FOR WHICH AED WAS DISPENSED

Epilepsy is a chronic disease and requires long term treatment. The decreased duration of AED dispensed is directly proportional to an increase in the number of visits to health facilities or pharmacies. In the present study, a treatment gap was seen in 60.0% and 34.5% PWE who were dispensed AED for ≤15 days and >15 days, respectively. (Table 35) These findings are in concordance with that of a systematic review conducted by King *et al* (2018)[77].

TREATMENT GAP AND SELF-REPORTED WAITING TIME AT THE HOSPITAL

The time consumed in waiting at a healthcare facility has indirect cost implications for PWE or their caregivers. In the present study, the treatment gap was observed in 22 (51.2%) PWE who reported ≥1 hour and 6 (37.5%) subjects reported <1 hour of the waiting period in a health care facility. (Table 36) In a study conducted by Xie and Or (2017)[78] it was reported that patients' perceived waiting periods can lead to overall dissatisfaction with health care services that can further influence their healthcare-seeking behaviour and the treatment gap.

TREATMENT GAP AND COUNSELLING FOR TREATMENT COMPLIANCE

Counselling is an important aspect of treatment. PWE and their caregiver should be counselled about the significance of regular treatment and the consequences of non-compliance at length. In the present study, only a 10.7% treatment gap was seen among the subjects who reported that they were counselled by healthcare professionals and 80.6% treatment gap in subjects who were not counselled. (Table 37) The association between the treatment gap and counselling was statistically significant.

TREATMENT GAP AND DISTANCE FROM HOME TO HEALTH FACILITY

In the present study, 47.4%, 50.0% and 46.7% treatment gap were observed in ≤5 km, 6-10 km and ≥11 km distance of PWE's home from a health facility, respectively. (Table 38) The findings of the present study are comparable to that of a study conducted by Mbuba *et al* (2012)[49] who reported a treatment gap of 41.1% in PWE living within 10 km and 54.7% in PWE living >10 Km from health facility. Another study by Wagner *et al* (2020)[72] reported 62.8% and 64.7% non-adherence in PWE living <5 Km and ≥5 km of health facility, respectively.

TREATMENT GAP AND MODE OF TRANSPORT

PWE usually face some restrictions to drive a vehicle during AED doses titration. Even if they have personal vehicles available, they need someone to drive them to the health care facility during this period. In the present study, a treatment gap of 54.8% and 42.9% was observed in PWE who used a personal vehicle and PWE who used public transport, respectively. (Table 39) As revealed by Wagner *et al* (2020)[72], the facility of personal transport is one of enabling factors influencing health care seeking behaviour of individuals to reduce the treatment gap, however, the cost associated with personal transport is an impeding factor and increases the treatment gap.

TREATMENT GAP AND HEALTH INSURANCE

With the rise in the cost of living and healthcare, health insurance is a must. The government has implemented the Ayushman Bharat Yojana based on socio-economic and caste census. In the present study, a treatment gap of 52.2% was observed in PWE who didn't have health insurance. (Table 40) Even in PWE who had health insurance, 30.8% treatment gap was seen because mostly health insurance doesn't cover outpatient treatment. A study conducted in Birmingham by Szaflarski *et al* (2020)[79] reported that the availability of health insurance was a crucial predictor of whether or not PWE

sought out a specialist. Similarly, a study conducted in China, by Ding *et al* (2018)[80] reported that poor health insurance coverage is associated with the epilepsy treatment gap.

TREATMENT GAP AND COMORBIDITY

The presence of comorbidities with epilepsy influences the treatment-seeking behaviour and treatment outcomes. In the present study, treatment gap was seen in 53.3% subjects with comorbidity and 45.5% without any comorbidity (p=0.299) (Table 41) A study conducted in West Bengal by Das *et al* (2007)[54] also reported a non-significant association between discontinuation of treatment and co-morbid psychiatric condition in PWE.

TREATMENT GAP AND FAMILY HISTORY

PWE who have a first or second degree relative with epilepsy may be familiar with the aetiology or treatment options available. Knowledge about epilepsy is one of the key factors that determine the treatment gap. In the present study, 33.3% treatment gap was observed in PWE who had a family history of epilepsy and 50.0% treatment gap in PWE who didn't have a family history of epilepsy. (Table 42)

TREATMENT GAP AND SUBSTANCE USE

Substance use is an independent risk factor for epilepsy. Alcohol, tobacco, and other addictive substances are well-known deterrents to seek medical care. In the present study, treatment gap was observed in 84.5% of PWE who reported substance use as compared to 41.2% of those without substance use. The association was statistically significant. (Table 43) Similarly, in a study conducted in Tanzania by Hunter *et al* (2016)[74] it was reported that the treatment gap among the PWE who were consuming alcohol was 57.5% as compared to 26.7% PWE who were not consuming alcohol.

REASONS FOR NON-COMPLIANCE/NON-ADHERENCE WITH AED AMONGST SUBJECTS WITH TREATMENT GAP

Non-compliance and non-adherence with the appropriately prescribed treatment regimen constitute the secondary treatment gap or therapeutic gap. Various studies have reported these factors under various headings. The reasons for non-compliance and non-adherence can be broadly classified as voluntary and involuntary. In the present study, the voluntary reasons included: PWE or their caregiver didn't want to buy an AED because they were seizure-free, seizures were not under control despite treatment, having side effects with AED, decreasing dosage without consulting the doctor to check if any problem would occur, had some other work. The involuntary reasons included forgetfulness, couldn't afford to buy medicine, stock out of medicine, didn't have means of transport to go and get AEDs, and unsupportive family. (Table 44) Similar reasons were reported by Panagariya *et al* (2018)[11] for non-compliance, who observed treatment cost, long duration of treatment, non-availability of AEDs, and more than once daily regimen was responsible for the same. Mbuba *et al* (2012)[49] has reported a long duration of treatment, negative attitudes to epilepsy, as a factor for non-adherence. Das *et al* (2007)[54] reported unemployment, treatment cost, unavailability of AED, beliefs about epilepsy, and frustration as the key factors leading to the discontinuation of epilepsy treatment. Srivastava *et al* (2021)[50] conducted a study in paediatric age group in rural Pune and reported poor accessibility, the loss of wage for visiting health facilities in the city, and unaffordability as factors for poor compliance.

DISTRIBUTION OF SUBJECTS AS PER THEIR KNOWLEDGE AND BELIEFS REGARDING EPILEPSY

In the present study, 30.5% of subjects or their caregivers had heard about epilepsy before their diagnosis but 59.0% didn't know the cause of epilepsy. One-third subjects believed it to be a brain disorder, whereas 3.3%, 11.5% and 19.7% believed it was caused by God's

curse, reflection from water or mirror, and Karma, respectively. A majority believed that the AED prescribed to them will cure epilepsy. (Table 45)

Previous studies reported that the proportion of PWE who had heard about epilepsy before their diagnosis varied from 32.0% to 99.0% and 38% to 72.7% didn't know the cause of epilepsy. Subjects who believed it to be a mental illness ranged from 27.0% to 41.0%. However, 80.0% subjects believed epilepsy is curable. [15,50,52]

SUMMARY AND CONCLUSION

The present study was a community-based cross-sectional study and was carried out in the rural field practice area of the Department of Community Medicine, Dayanand Medical College and Hospital, Ludhiana.

- A total of 31043 population was screened, door to door, with Placencia's 9-item screening questionnaire.
- There were 195 screened positive individuals and out of these 4 refused to participate and 4 died before clinical evaluation and 187 were further evaluated by the neurology team. These 187 were diagnosed as Active epilepsy, Inactive epilepsy, Acute Symptomatic seizure, Febrile Seizure, Single seizure, Psychogenic Non-epileptic seizure, Syncope.
- The subjects with active epilepsy and inactive epilepsy were further studied for prevalence and the subjects with active epilepsy were further studies for sociodemographic profile and determinants of treatment gap.

Lifetime prevalence of epilepsy

- The lifetime prevalence of epilepsy was 2.5 per thousand study population and ranged from 1.7 in 50–59 year age group to 3.4 in ≥80 year age group.
- The gender-wise lifetime prevalence was 2.7 in males and 2.3 in the female per thousand population, respectively.

Prevalence of active epilepsy

- The overall prevalence of active epilepsy was 1.96 per thousand study population and ranged from 0.8 in the 50–59 year age group to 2.9 in 70–79 year age group.
- The gender-wise prevalence was 2.1 in males and 1.9 in females per thousand population, respectively.

Socio-demographic profile of subjects with active epilepsy

- The majority of subjects (91.8%) followed the Sikh religion.
- Unmarried and married represented 47.5% and 45.9% of subjects with active epilepsy.
- There were 78.7% of subjects who had formal education and 21.3% were illiterate.
- There were 29.6% subjects who were unemployed, 27.9% were engaged in household work, 24.5% economically productive work and 18.0% were studying.
- Nearly half (50.8%) of the subjects were residing in joint families.
- About two-thirds (67.2%) of subjects belonged to the lower middle class.
- The mean monthly family income of study subjects was ₹13500 ± 2121.32.

Treatment Gap in subjects with active epilepsy

- Treatment gap was observed in 49.2% subjects with active epilepsy.
- There was 3.3% and 45.9% primary (diagnostic) and secondary (therapeutic) treatment gap, respectively.
- The treatment gap was seen in 61.1% subjects in 20–59 year age group.
- Treatment gap was observed in 56.0% females and 41.1% males.
- Treatment gap was 58.3% among illiterate PWE while 44.7% in subjects who had formal education.
- Treatment gap was 71.4% among the married subjects as compared to 25.8% in unmarried/widowed/ divorced.
- The treatment gap observed in subjects residing in nuclear and joint families was almost the same.
- The maximum treatment gap was observed in 56.8% subjects who belonged to lower-middle class socioeconomic status.

- Subjects who were having seizures frequently (at least once in a fortnight) had 28.6% treatment gap and almost twice (57.9%) in PWE who had seizure frequency >15 days.
- PWE who sought non-allopathic and allopathic treatment after a first seizure had 73.3% and 38.6% treatment gap, respectively.
- Subjects who sought treatment more than one month after the first seizure had 70.0% treatment gap.
- PWE on monotherapy and once-daily regimen had a 50.0% and 66.7% treatment gap, respectively.
- The subjects who had interrupted availability of AED had a 50.0% treatment gap.
- Treatment gap was found among 34.5% and 60.0% subjects who were dispensed AEDs for more than 15 days and less than 15 days, respectively.
- Counselling was associated with better treatment compliance.
- Subjects who reported substance use during the duration of treatment had 84.5% treatment gap.
- There was no significant relationship between treatment gap and distance from home to health facility, health insurance coverage, comorbidity among subjects, and family history of epilepsy.
- Age, marital status, lower socioeconomic status, current seizure frequency, type of treatment sought after the first seizure, duration between first seizure and treatment sought, the duration for which AEDs were dispensed, counselling for treatment compliance, mode of transport, and substance abuse, were significantly associated with treatment gap.
- About two-thirds (69.5%) of subjects had not heard about epilepsy before their diagnosis and 59.0% didn’t know the cause of epilepsy. However, majority believed that the prescribed AED will cure their epilepsy.

- Subjects who believed epilepsy is caused by God’s curse, karma and reflection from water or mirror were 3.3%, 19.7% and 11.5% respectively.
- One-third of subjects knew that epilepsy is a brain disorder.

LIMITATIONS

- The study was confined to a rural area of Ludhiana district and its results may not be a true representative of Punjab and India.
- Non-response bias- Four screened positive individuals refused to participate in the study.
- Recall bias- PWE were asked retrospective information about many determinants and since epilepsy is a chronic disease that can cover many decades of life. Hence, recall bias is unavoidable. Illiteracy may have acted as a confounding factor.
- Events that occurred at home were self-reported by subjects and their objective analysis was not feasible.
- There is a stigma associated with epilepsy which may have led to the concealment of information.
- In some cases, the definitive final diagnosis could not be reached in absence of supportive evidence that could have been provided by further investigations, e.g., Magnetic Resonance Brain, which were beyond the scope of this study.

RECOMMENDATIONS

On the basis of the results obtained, following are the recommendations:

- Awareness generation regarding epilepsy and its causes by health care workers at the community level.
- Alleviate the concerns of the PWE and their caregivers.
- Rehabilitation of the PWE by providing local employment opportunities.
- An epilepsy registry can be established for longitudinal studies to assess the risk factors associated with epilepsy and its treatment gap.
- In-depth qualitative research studies are needed to study determinants of the epilepsy treatment gap.
- Multicentric study involving both urban and rural areas to ensure a proper representative study sample to generalize the findings to Punjab and India
- In light of the paucity of neurology services, primary health care staff and physicians can be trained to recognize the needs of PWE and ensure proper counselling regarding the duration of treatment, expected side effects and follow-up.
- Outreach camps for PWE in public-private partnership can be organized and PWE can get prescriptions filled at the nearest public health facility.
- Uninterrupted and continuous supply of AEDs should be ensured in the public health system.
- Involving self-help groups or non-government organizations to ensure compliance to treatment, regular follow-up with a physician,
- Education for prevention of substance use.
- Health insurance should include OPD services for epilepsy under a cashless scheme.

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KEY TO MASTER CHART

Age	Age in completed years
YOS	Years of schooling
SESS	Socioeconomic status scale
MUP	Modified Udai-Pareek
BP	Blood pressure

Can subject answer for himself/herself		**Caste**	
Yes		Schedule Caste	1
No		Non Schedule caste	2
If no who will		**Living**	
Not applicable	0		
Mother	1		
Father	2	Alone	1
Daughter/Son	3	With spouse	2
Gender		With Parents	3
Male	1	With children	4
Female	2	**Type of family**	
Village		Nuclear	1
Bhikhi	1	Joint	2
Gopalpur	2	**Working**	
Jagera	3	Working	1
Jhammat	4	Not working	2
Kalahar	5	Previously working	3
Khattra	6	Household work	4
Khera	7	**If working**	
Kilahans	8	Not applicable	0
Lehra	9	Agriculture	1
Pandherkheri	10	Business	2
Pohir	11	Service	3
Rangian	12	Labourer	4
Rurka	13	Student	5
Saharanmajra	14	**If previously working**	
Siahar	15	Not applicable	0
Religion		Left Job due to epilepsy	1
Hindu	1	**Ethnicity**	
Sikh	2	Punjabi	1
Muslim	3	Migrant	2

Marital Status		SESS MUP Score	SESS MUP Grade
Single	1	>43	1
Widow	2	33-42	2
Widower	3	24-32	3
Divorce	4	13-23	4
Married	5	<13	5

Duration since first seizure		**Name of medicine**	
<5 years	1	Not applicable	0
5-9 years	2	Carbamazepine	1
≥10 years	3	Phenytoin	2
Whom did you contact at that time		Phenobarbital	3
Neurology	**1**	Levetiracetam	4
Other allopathic specialties	**2**	Clobazam	5
Non-allopathic doctors	**3**	Oxcarbazepine	6
Description of current seizure frequency		Sodium valproate	7
≤ 15 days	1	Sodium valproate and valproic acid	8
>15 days	2	Lithium	9
Was the treatment started		**Are you currently on treatment with AED**	
Yes	1	Not applicable	0
No	2	Yes	1
When was the treatment sought after first seizure		No	2
		If no, did you stop the medicine on advice of your doctor	
Never	0		
<1 month	1	Not applicable	0
>1 month	2	Yes	1
Type of treatment sought after first seizure		No	2
Not applicable	0		
Allopathic	1		
Non-allopathic	2		

How did you feel after starting treatment		**If no to previous question why did you stop the medicine**	
Not applicable	0	Not applicable	0
Much better	1	Excessive Alcohol	1
Slightly better	2	Had household work	2
Better	3	Had to go to work	3
No improvement	4	Didn’t had time to get it	4
Number of different AED prescribed for epilepsy		I was seizure free	5
Not applicable	0	Seizure was not under control despite treatment	6
One	1		
More than one	2	Having side effects with medicine	7
In a day how many times do you have to take each medicine for epilepsy		Didn’t have means of transport to go and get it	8
Not applicable	0	**Specify side effect if present**	
Once	1	Not applicable	0
≥Twice	2	Headache	1
Can you name your medicine		Heaviness in head	2
Not applicable	0	Sedation in day	3
Yes	1	Swelling and pain in calf muscle of both legs	4
No	2		

Do you forget to take seizure medication sometime		**Do you sometime skip your medication**	
Not applicable	0	Not applicable	0
Yes	1	Yes	1
No	2	No	2
If yes, reason for skipping the medicine			
Not applicable	0	Didn’t Have Means Of Transport To Go & Get It	8
Could Not Afford To Buy Medicine	1	Didn’t Have Time To Get It	9
Tried But Could Not Find A Place To Buy Medicine	2	Had To Go To Work	10
To Try Alternate Medicine	3	Had Household Work	11
Didnt Want To Buy It	4	Didn't Want To Travel	12
Was Seizure Free	5	Family Is Not Supportive	13
Seizure Were Not Under Control Despite Treatment	6	Got Fed Up Of Taking Medicine	14
Side Effects with Medicine	7	To Check If any Problem Will Occur From Decreasing Dose From thrice daily to twice daily	15

Specify side effects if present		**From where do you get medicine**	
Not applicable	0	Not applicable	0
Headache	1	Government medical college	1
Heaviness in head	2	Government district hospital	2
Sedation in day	3	Sub district hospital	3
Swelling and pain in calf muscle of both legs	4	Community health centre	4
Weekness	5	Pharmacy	5
Increased sleepiness	6	Quack	6
Vertigo	7	Private medical college	7
Constipation	8	Private clinic	8
		Private hospital	9

Is medicine always available?		**Is doctor always available when you go to health facility**	
Not applicable	0	Not applicable	0
Yes	1	Yes	1
No	2	No	2
If medicine is not always available at regular source		**Grading of distance of health facility from your house in nearest kilometer**	
Not applicable	0	Not applicable	0
Miss taking medicine	1	≤5	1
Buys or obtain from alternate source	2	6-10	2
		≥11	3

Mode of transport		**Were you counseled by health care personnel doctor on need of regular medication use and consequences of non-adherence**	
Not applicable	0		
Personal vehicle	1	Not applicable	0
By foot	2	Yes	1
Public transport	3	No	2
Does this distance to the health facility keep you from refilling your medication		**Were you referred from one centre to other**	
		Not applicable	0
Yes	1	Yes	1
No	2	No	2
Do you have difficulty travelling to health facility		**If yes, did you follow up at the referred center**	
Not applicable	0	Not applicable	0
Yes	1	Yes	1
No	2	No	2
Who accompanies you		**If you did not follow up then why**	
Not applicable	0	Not applicable	0
Spouse	1	No specific reason	1
Mother	2	**Does attitude of health care provider towards your illness keep you from going to clinic**	
Father	3		
Sibling	4		
Alone	5		
Son/ Daughter	6		
Grandson	7	Not applicable	0
Maternal uncle	8	Yes	1
Grandfather/ Grandmother	9	No	2

Are you satisfied with the quality of medical care at the health facility		**Do you believe that AED prescribed now will control your epilepsy**	
Not applicable	0	Not applicable	0
Yes	1	Yes	1
No	2	No	2
For how much period drugs are dispensed at a time		Don’t know	3
Not applicable	0	**Any comorbid conditions**	
≤15	1	Yes	1
>15	2	No	2
For how long do you have to wait at hospital		**Any concomitant medication**	
Not applicable	0	Yes	1
<1	1	No	2
≥1	2	**Any history of fever**	
Have you ever heard of epilepsy before		Yes	1
Yes	1	No	2
No	2	**Any history of headache**	
Is epilepsy a		Yes	1
Brain disorder	1	No	2
Enumerate symptoms	2	**Any history of focal neurological deficit**	
Hereditary	3		
Don’t know	4		
What do you think epilepsy is caused by		Yes	1
		No	2
Reflection from water/mirror	1	**Any history of febrile seizures in childhood**	
God’s curse	2		
Karma	3	Yes	1
Don’t know	4	No	2
Other reasons	5		

Any history of childhood encephalopathy		**If yes relation**	
Yes	1	Not applicable	0
No	2	Mother	1
Any history of neonatal hypoglycemia		Father	2
Yes	1	Cousin	3
No	2	**Consanguineous parents**	
Any history of kernicterus			
Yes	1	Yes	1
No	2	No	2
Any history of significant birth history		**Any other significant history**	
Yes	1	Yes	1
No	2	No	2
Any history of head injury		**Sleeping area**	
Yes	1	Not applicable	0
No	2	Sleeps alone	1
Any history of CNS infection		Shares a bedroom but sleep on separate beds	2
		Shares a bed	3
Yes	1	**Diet**	
No	2	Vegetarian	1
Any history of brain surgery		Non-vegetarian	2
Yes	1	Eggetarian	3
No	2		
Does any family member have a history of seizure or epilepsy		**Alcohol during treatment period**	
		Never	1
Yes	1	Occasionally	2
No	2	Daily	3

Smoking during treatment period		Regularity	
		Not applicable	0
Never	1	Regular	1
Daily	2	Irregular	2
Any other substance abuse		**Does seizure occur just before after or no relation**	
None	1		
Afeem	2	Not applicable	0
Doda	3	Just before menses	1
Zarda	4	No relation with menses	2
Any substance abuse		**History of birth defect in children**	
Yes	1		
No	2	Not applicable	0
Health insurance		Yes	1
None	1	No	2
Job benefit	2	**Any child with epilepsy**	
Government	3	Not applicable	0
Age at menarche		Yes	1
Not applicable	0	No	2
Last menstrual period		**Remarks**	
Not applicable	No	Not applicable	0
Duration in days		**Systolic BP/ Diastolic BP/ Pulse**	
Not applicable	0	Not applicable	0
Flow		**Treatment gap**	
Not applicable	0	Yes	1
Normal	1	No	2

GLOSSARY OF TERMS

- **Nuclear Family**includes husband, wife and dependent unmarried children, related by blood, adoption, marriage and who live together in the same house, sharing the same kitchen and meet their expenses from the same pocket.
- **Joint Family**is a group of people who are either related by blood, marriage or adoption, living together in the same house and sharing the same kitchen. It is a lateral extension of the nuclear family where multiple sibling families live together.
- **Monotherapy**: Treatment with a single antiepileptic drug.
- **Polytherapy**: Treatment with more than one antiepileptic drug.

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Date 20/4/2021

The Principal,
DMC, Ludhiana

Subject: **Approval of Plan of Thesis.**

This is to inform you that the Faculty of Medical Sciences in its meeting held on 22.01.2021 has approved the plan of thesis of **Dr. Aman Bansal**, a student of your college for **MD Community Medicine** along with the names of Supervisor/Co-Supervisor as under:-

Topic Plan of Thesis
Prevalence of epilepsy and determinants of treatment gap in people with epilepsy in rural Ludhiana

Supervisor
Dr. Anurag Chaudhary
Prof. & Head,
Dept. of Community
Medicine,

Co-Supervisor
Dr. Gagandeep Singh
Prof. & Head,
Dept. of Neurology,
DMCH, Ludhiana.
Dr. Sangeeta Girdhar
Prof.,
Dept. of Community Medicine,
DMCH, Ludhiana.

The student has to submit the three copies of thesis (along with PDF format) , to the Controller of Examinations, BFUHS, Faridkot, at least six months before the commencement of theory examination, if he/she is otherwise eligible to take the examination. He /She must directed to attach a photocopy of this letter with the forwarding letter while submitting thesis to the University along with the letter of approval of University for change of supervisor/Co-Supervisor, change of topic,(if any).

SP Singh
Dr. S P Singh MS(Oph)
Controller of Examinations

Note :

1. ***If any discrepancy found regarding topic of thesis or Supervisor/Co-Supervisor, inform undersigned within one month after issue of this letter.***
2. *The student may submit the thesis as per the schedule already conveyed i.e for May/June examination 30th Nov of the preceding the year of examination and for Nov/Dec examinations 31st May of the year of examination.*

Gmail **Dr.Aman Bansal <spmdmcbansal@gmail.com>**

permission for using epilepsy screening questionnaire

Marcelo Placencia <mepa237416@gmail.com> Mon, Aug 5, 2019 at 10:21 PM
To: "Dr.Aman Bansal" <spmdmcbansal@gmail.com>

With pleasure Dr. Bansal. Please use it. It will be nice to know our questionnaire is useful in your survey in India.
Please dotn't hesitate to contact me if you need some clarification.
With best regards.
Marcelo Placencia, MD, MP

El lun., ago. 5, 2019 5:55, Dr.Aman Bansal <spmdmcbansal@gmail.com> escribió:

> Respected sir,
>
> I have found your screening questionnaire used in 'Validation of a screening questionnaire for the detection of epileptic seizures in epidemiological studies' is useful for my thesis study on EPILEPSY.
>
> Kindly allow me to use and translate it in our community setting.
>
> Regards,
> Dr. Aman Bansal, MBBS
> Post-Gradute Resident
> Department of Community Medicine
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Serial No	can subject answer for himself	if no who will	NAME	AGE	Gender	Village	YOS	RELIGION	CASTE	Marital status	LIVING with	TYPE OF FAMILY	WORKING	IF WORKING	IF PREVIOUSLY WORKING	INCOME IN RUPEE PER MONTH	ETHNICITY	SESS MUP SCORE	SESS MUP GRADE	DURATION SINCE FIRST SEIZURE IN MONTHS
1	1	0	DS	55	1	1	5	2	2	5	2	1	1	1	0	8000	1	29	3	132.0
2	2	1	AS	9	1	2	6	2	1	1	3	1	1	5	0	10,000	1	26	3	48.0
3	1	0	JS	47	1	2	10	2	2	5	2,3,4	2	1	2	0	15000	1	25	3	240.0
4	2	1	J	18	2	2	8	2	1	1	3	1	1,4	5	0	6000	1	18	4	180.0
5	1	0	PK	58	2	2	5	2	1	5	2,4	1	4	0	0	3000	1	23	4	288.0
6	1	0	CS	60	1	3	10	2	2	5	2,4	2	1	4	0	8000	1	20	4	124.0
7	1	0	MS	36	1	3	5	2	1	5	2,4	1	1	4	0	9000	1	18	4	25.0
8	1	0	MK	22	2	3	8	2	1	1	3	2	3	5	1	9000	1	21	4	168.0
9	1	0	S	45	2	3	5	2	2	5	2,4	2	4	0	0	10,000	1	21	4	324.0
10	1	0	GS	70	1	4	10	2	2	3	4	2	3	1	1	25000	1	34	2	432.0
11	2	2	HK	8	2	4	2	2	1	1	3	2	1	5	0	7000	1	24	3	60.0
12	1	0	JK	5	2	4	1	2	1	1	3	1	1	5	0	8000	1	18	4	42.0
13	2	2	K	22	1	4	0	2	1	1	3	2	2	0	0	10,000	1	17	4	48.0
14	1	0	BK	40	2	5	0	2	1	5	2,3	1	4	0	0	4000	1	15	4	216.0
15	1	0	N	38	2	5	5	1	2	5	2	1	4	0	0	8000	1	23	4	372.0
16	1	0	H	54	2	6	4	2	2	5	3,4	1	4	0	0	6500	1	16	4	72.0
17	2	1	MK	20	2	6	6	2	2	1	3	1	4	0	0	12000	1	25	3	216.0
18	1	0	PK	26	2	6	10	2	1	5	2	1	3	0	0	8500	1	20	4	60.0
19	1	0	PK	9	2	6	4	2	1	1	5a	1	1	5	0	5500	1	20	4	36.0
20	1	0	S	15	2	6	2	3	2	1	3	1	4	0	0	6500	1	14	4	48.0
21	1	0	TS	45	1	6	8	2	2	5	2,4	1	1	4	0	4000	1	19	4	96.0
22	1	0	MS	15	1	7	11	2	1	3	1	1	1	5	0	20000	1	25	3	84.0
23	1	0	HS	42	1	8	10	2	1	1	3	2	1	4	0	4500	1	19	4	492.0
24	2	1	JS	3	1	8	0	2	1	1	3	2	2	0	0	20,000	1	25	3	36.0
25	2	1	JS	25	1	8	10	2	2	1	3	1	1	4	0	9000	1	20	4	9.0
26	1	0	MS	21	1	8	15	2	1	1	3	1	1	5	0	17000	1	25	3	120.0
27	1	0	JK	31	2	9	12	2	1	5	2	2	4	0	0	11,000	1	24	4	78.0
28	2	1	KS	21	1	9	5	2	1	1	3	1	2	0	0	8500	1	19	4	120.0
29	1	0	S	30	2	9	0	2	2	5	2,4	2	4	0	0	15000	1	21	4	36.0
30	1	0	VK	23	1	9	10	1	1	5	2,3	2	1	4	0	8000	1	19	4	252.0
31	1	0	LS	72	1	10	0	2	1	5	2,4	2	3	4	1	5000	1	17	4	90.0
32	1	0	PS	45	1	10	5	2	1	5	2,4	1	1	4	0	8000	1	18	4	60.0
33	2	3	DK	47	2	11	0	2	1	5	2	2	4	0	0	20000	1	25	3	2.0
34	2	1	F	22	1	11	0	3	1	1	3	1	2	0	0	8000	1	16	4	264.0
35	2	2	GK	7	2	11	1	2	1	1	3	1	1	5	0	10000	1	22	4	48.0
36	1	0	GK	48	2	11	10	2	1	5	2	1	3,4	0	1	10000	2	20	4	336.0
37	1	0	HK	35	2	11	5	2	1	5	2	1	4	0	0	9000	1	19	4	120.0
38	1	0	RS	21	1	11	10	2	1	1	3	2	1	5	0	12000	1	20	4	180.0
39	1	0	SK	38	2	11	7	2	2	5	2,4	1	4	0	0	16000	1	23	4	216.0
40	1	0	BS	72	1	11	8	2	2	5	2	2	3	0	1	20000	1	27	3	216.0

Serial No	Duration since first seizure grading	WHOM DID YOU CONTACT AT THAT TIME	DURATION SINCE LAST SEIZURE IN MONTHS	WHOM DID YOU CONTACT AT THAT TIME	CURRENT FREQUENCY OF DOMINANT SEIZURES	DESCRIPTION OF PRIOR SEIZURE	WAS THE TREATMENT STARTED	When was the treatment sought after first seizure	TYPE OF ANTIEPILEPTIC TREATMENT	HOW DID YOU FEEL AFTER STARTING TREATMENT	NUMBER OF DIFFERENT AED PRESCRIBED FOR EPILEPSY	IN A DAY HOW MANY TIMES DO YOU HAVE TO TAKE EACH MEDICINE FOR EPILEPSY	CAN YOU NAME YOUR MEDICINE	IF YES THEN NAME	ARE YOU CURRENTLY ON TREATMENT WITH AED	IF NO DID YOU STOP MEDICINE ON ADVICE OF YOUR DOCTOR
1	3	3	60.0	1	2	6	1	1	2	1	2	2	2	0	1	0
2	1	1	24.0	1	2	6	1	1	1	1	1	1	1	1	1	0
3	3	2	1.0	3	2	6	1	1	1	3	2	2	1	1,8	1	0
4	3	1	4.0	1	2	6	1	1	1	3	2	2	2	0	1	0
5	3	1	24.0	2	2	1	1	1	1	3	2	2	2	0	1	0
6	3	1	24.0	3	2	4	1	1	1	1	2	1	2	0	1	0
7	1	2	25.0	1	2	7	1	1	1	1	1	2	2	0	2	1
8	3	2	3.0	3	2	6	1	1	1	1	2	2	2	0	1	0
9	3	2	18.0	2	2	6	1	2	1	1	1	1	2	0	1	0
10	3	2	36.0	2	2	3,4	1	1	2	3	2	2	2	0	1	0
11	1	2	0.0	3	1	7	1	1	1	4	2	2	2	0	2	1
12	1	2	42.0	2	1	7	1	1	1	3	2	2	1	1	2	1
13	1	1	9.0	1	2	6	1	1	1	1	2	2	2	0	1	0
14	3	2	168.0	3	2	6	1	2	1	3	2	2	2	0	2	1
15	3	2	78.0	1	2	6	1	1	1	1	1	1	1	8	1	0
16	2	1	21.0	3	1	1	1	1	1	4	2	1	2	0	1	0
17	3	2	198.0	2	1	3	1	1	1	3	1	2	2	0	1	0
18	1	1	0.1	1	1	2	1	1	1	4	2	2	1	0	1	0
19	1	1	0.3	3	1	1	1	1	2	2	1	2	2	0	1	0
20	1	3	0.0	3	1	1	1	1	2	4	2	2	2	0	1	0
21	2	2	12.0	2	2	4	1	1	1	3	2	2	2	0	2	2
22	2	2	13.0	2	2	2	1	1	2	3	1	2	1	7	1	0
23	3	3	0.3	2	1	1	1	2	2	3	2	2	2	0	1	0
24	1	3	10.0	1	1	1	1	1	2	2	2	2	1	7	1	0
25	1	3	9.0	3	2	0	1	1	2	3	1	2	2	0	1	0
26	2	2	84.0	1	2	6	1	1	1	3	2	2	1	3	1	0
27	2	2	36.0	2	2	9	1	1	1	4	1	2	1	4	1	0
28	2	2	4.0	2	2	1	1	1	1	3	1	2	2	0	1	0
29	1	1	10.0	3	2	5	1	1	1	3	1	1	2	0	1	0
30	3	2	6.0	3	1	2	1	1	1	3	1	2	2	0	1	0
31	2	2	0.0	2	1	1	1	1	1	1	1	1	2	0	1	0
32	1	2	0.0	2	2	9	1	2	1	4	2	2	2	0	2	2
33	1	2	0.0	2	2	7	1	1	1	1	1	2	1	4	1	0
34	3	2	1.0	2	1	1	1	2	1	3	1	2	1	1	1	0
35	1	2	60.0	2	1	2	1	1	1	1	2	2	1	7	1	0
36	3	2	4.0	2	1	0	1	1	1	1	2	1	1	2	1	0
37	2	2	0.2	2	2	3	1	1	1	3	1	1	2	0	1	0
38	3	2	60.0	2	2	6	1	1	1	1	1	2	1	6	1	0
39	3	3	1.0	2	2	0	1	1	2	4	1	2	2	0	1	0
40	3	2	18.0	1	2	1	1	2	1	3	1	1	2	0	2	2

Serial No	IF NO TO PREVIOUS QUESTION WHY DID YOU STOP THE TREATMENT	SPECIFY SIDE EFFECT IF PRESENT	DO YOU FORGET TO TAKE SEIZURE MEDICATION SOMETIME	DO YOU SOMETIMES SKIP YOUR MEDICATION	IF YES REASON FOR SKIPPING THE MEDICINE	SPECIFY SIDE EFFECT IF PRESENT	FROM WHERE DO YOU TAKE MEDICATION	IS MEDICINE ALWAYS AVAILABLE	IF MEDICINE IS NOT ALWAYS AVAILABLE AT REGULAR SOURCE	IS DOCTOR ALWAYS AVAILABLE WHEN YOU GO TO HEALTH FACILITY	DISTANCE OF HEALTH FACILITY FROM YOUR HOUSE IN NEAREST KILOMETER	GRADING OF DISTANCE OF HEALTH FACILITY FROM YOUR HOUSE IN NEAREST KILOMETER	MODE OF TRANSPORT	HOW MUCH TIME DOES IT TAKE TO TRAVEL TO HEALTH FACILITY FROM YOUR HOME IN HOURS
1	0	0	2	1	5	0	9	1	0	1	35	3	3	90
2	0	0	2	2	0	0	9	1	0	1	30	3	1	40
3	0	0	1	2	0	0	8,9	1	0	1	5	0	1	15
4	0	0	2	2	0	0	7	1	0	1	25	3	3	60
5	0	0	2	2	0	0	7	1	0	1	10	2	1	30
6	0	0	2	2	0	0	9	1	0	1	2	1	1	10
7	0	0	2	2	0	0	1	1	0	1	180	3	1	240
8	0	0	1	1	5	0	2,8,9	1	0	1	5	1	1	15
9	0	0	1	1	7	5	8,9	1	0	1	5	1	1	7
10	0	0	2	1	9	0	9	1	0	1	6	2	1	8
11	0	0	2	2	0	0	9	2	2	0	4	1	3	0
12	0	0	2	2	0	0	8,9	1	0	1	20	3	1,3	30
13	0	0	2	1	5	0	9	1	0	1	36	3	1	60
14	0	0	2	2	0	0	8,9	1	0	2	1	1	2	10
15	0	0	2	2	0	0	5	1	0	0	1	1	2	10
16	0	0	2	1	6,11	0	8	1	0	1	35	3	3	65
17	0	0	2	2	0	0	4	2	2	1	5	1	1	15
18	0	0	2	1	6,14	0	9	1	0	1	30	3	1	60
19	0	0	1	1	7,13	0	8	1	0	1	5	1	1	60
20	0	0	2	2	0	0	8	1	0	1	10	2	2	30
21	1	0	1	1	4	0	9	1	0	1	25	3	3	50
22	0	0	2	2	0	0	2,8,9	1	0	1	3	1	1	15
23	0	0	2	2	0	0	9	1	0	1	3	1	2	60
24	0	0	2	2	0	0	1	1	0	1	120	3	3	200
25	0	0	2	2	0	0	8,9	1	0	1	3	1	1	15
26	0	0	2	2	0	0	8,9	1	0	1	30	3	1	60
27	0	0	1	2	0	0	8	1	0	1	7	2	1	20
28	0	0	2	2	0	0	8	1	0	1	10	2	1	15
29	0	0	1	1	9,11,14	0	9	1	0	1	3	1	1	15
30	0	0	1	1	7,11	6	8	1	0	1	30	3	1,3	60
31	0	0	2	1	5	0	8,9	1	0	1	25	3	1	60
32	3	0	1	1	10	0	8	1	0	1	15	3	1	30
33	0	0	2	2	0	0	3	1	0	1	2	1	2	15
34	0	0	1	2	0	0	9,5	1	0	2	20	3	1	40
35	0	0	2	1	14,15	0	8,9	1	0	1	100	3	1	120
36	0	0	1	1	1,2,7,8,14	7	5	1	0	1	180	3	3	180
37	0	0	1	1	11	0	4	2	2	1	5	1	1	15
38	0	0	2	2	0	0	7	1	0	2	30	3	3	60
39	0	0	2	1	9,10	0	5	1	0	1	1	1	1	15
40	4,8	0	2	1	5,8,9,13	0	7,9	1	0	1	1	1	1	0

Serial No	DOES THIS DISTANCE TO HEALTH FACILITY KEEP YOU FROM REFILLING YOUR MEDICIATION	DO YOU HAVE DIFFICULTY IN TRAVELING TO HEALTH FACILITY	WHO ACCOMPANIES YOU	WERE YOU COUNSELLED BY HEALTH CARE PERSONNEL DOCTOR ON NEED OF REGULAR MEDICATION USE AND CONSEQUENCES OF NON ADHERENCE	treatment gap	WERE YOU REFFERED FROM ONE CENTRE TO OTHER	IF YES DID YOU FOLLOW UP AT THE REFERRED CENTRE	IF YOU DID NOT FOLLOW UP THEN WHY	DOES ATTITUDE OF HCP TOWARDS YOUR ILLNESS KEEP YOU FROM GOING TO CLINIC	ARE YOU SATISFIED WITH THE QUALITY OF MEDICAL CARE AT THE HEALTH FACILITY	FOR HOW MUCH PERIOD DRUGS ARE DISPENSED AT ONE TIME	FOR HOW LONG DO YOU HAVE TO WAIT AT HOSPITAL	HAVE YOU EVER HEARD OF EPILEPSY BEFORE	IS EPILEPSY A
1	2	1	0	2	1	2	0	0	2	1	2	2	2	4
2	2	2	3,4	1	2	1	1	0	2	2	2	1	2	1,3
3	2	2	0	2	1	2	0	0	2	1	1	2	1	4
4	2	2	2,3	1	2	2	0	0	2	1	2	2	2	2
5	2	2	6	1	2	2	0	0	2	1	1	2	2	4
6	2	2	0	1	2	2	0	0	2	1	1	1	2	2
7	1	1	1	1	2	2	0	0	2	1	2	2	2	4
8	2	2	3	2	1	2	0	0	2	1	1	2	2	4
9	2	2	1,4	2	1	2	0	0	2	1	1	2	2	1
10	2	2	6	2	1	2	0	0	2	1	2	1	2	4
11	0	0	0	1	2	0	0	0	2	0	2	1	2	4
12	2	2	2	1	2	2	0	0	2	1	1	2	2	4
13	1	1	2,3	2	1	1	1	0	2	1	2	2	2	2
14	2	2	5	2	2	2	0	0	2	1	1	1	2	4
15	2	2	1	1	2	2	0	0	2	1	2	2	1	1
16	1	1	6	2	1	2	0	0	2	1	1	2	2	1
17	2	2	3	1	2	2	0	0	2	1	1	2	2	4
18	2	2	1	2	1	2	0	0	2	1	2	2	2	1
19	2	2	9	2	1	2	0	0	2	1	1	1	1	1
20	2	1	2,3	2	2	2	0	0	2	2	1	2	2	4
21	2	2	1	1	1	2	0	0	2	1	1	2	1	4
22	2	2	2,3	1	2	1	1	0	2	1	2	2	1	1
23	2	1	2,4	1	2	2	0	0	2	1	2	1	2	4
24	2	1	2,3	1	2	2	0	0	2	1	2	2	2	1
25	2	2	2,3	2	2	0	2	1	2	1	1	1	2	1
26	2	2	3	1	2	2	0	0	2	1	2	2	1	1
27	2	2	1	1	1	2	0	0	2	1	1	2	2	2
28	2	2	0	2	2	2	0	0	2	1	1	2	1	2
29	2	2	0	2	1	2	0	0	2	1	1	2	2	4
30	2	1	2,3	2	1	2	0	0	2	1	2	2	1	1
31	1	1	7	2	1	2	0	0	2	1	2	2	2	4
32	2	2	5	2	1	2	0	0	2	1	1	1	2	4
33	2	2	6	1	2	2	0	0	2	1	1	1	2	1
34	2	1	2	2	1	2	0	0	2	1	1	1	2	1
35	2	1	3	2	1	1	1	0	2	1	2	2	1	2
36	2	1	1,6	2	1	2	0	0	2	1	2	2	1	2
37	2	2	4	2	1	2	0	0	2	1	1	2	1	4
38	2	1	3	2	2	2	0	0	2	1	2	2	2	4
39	1	1	1	1	1	2	2	1	2	1	1	1	1	4
40	1	1	1	2	1	2	0	0	2	1	2	2	2	4

Serial No	WHAT DO YOU THINK EPILEPSY IS CAUSED BY	DO YOU BELIEVE THAT MEDICINE AED PRESCRIBED NOW WILL CONTROL YOUR EPILEPSY	ANY COMORBID CONDITIONS	CONCOMITANT MEDICATION	ANY HISTORY OF FEVER	ANY HISTORY OF HEADACHE	ANY HISTORY OF FOCAL NEUROLOGICAL DEFICIT	ANY HISTORY OF FEBRILE SEIZURES IN CHILDHOOD	ANY HISTORY OF CHILDHOOD ENCEPHALOPATHY	ANY HISTORY OF NEONATAL HYPOGLYCEMIA	ANY HISTORY OF KERNICTERUS	ANY HISTORY OF SIGNIFICANT BIRTH HISTORY	ANY HISTORY OF HEAD INJURY	ANY HISTORY OF CNS INFECTION
1	4	1	2	2	2	2	2	2	2	2	2	2	2	2
2	1	1	1	1	1	2	1	1	2	2	2	2	1	2
3	4	1	2	2	2	2	2	2	2	2	2	2	1	2
4	3	1	2	2	2	2	2	2	2	2	2	2	2	2
5	4	1	2	2	2	1	2	2	2	2	2	1	2	2
6	4	1	2	2	2	2	2	2	2	2	2	2	2	2
7	5	1	2	2	2	2	2	2	2	2	2	2	1	2
8	5	1	2	2	2	2	2	2	2	2	2	2	2	2
9	3	1	1	2	2	2	2	2	2	2	2	2	2	2
10	5	1	1	1	2	2	2	2	2	2	2	2	2	2
11	5	0	2	2	2	2	2	2	2	2	2	2	2	2
12	4	0	2	2	2	2	2	2	2	2	2	2	2	2
13	1	1	1	2	2	2	2	2	2	2	2	1	2	2
14	4	1	2	2	2	2	2	2	2	2	2	2	2	2
15	1	1	2	2	2	2	2	2	2	2	2	2	2	2
16	4	2	1	2	2	2	2	2	2	2	2	2	2	2
17	5	1	2	2	2	2	2	1	2	2	2	1	2	2
18	4	1	2	2	2	2	2	2	2	2	2	2	2	2
19	4	1	2	2	2	2	2	2	2	2	2	2	1	2
20	4	3	1	2	2	2	2	2	2	2	2	2	2	2
21	4	2	2	2	2	2	2	2	2	2	2	2	1	2
22	4	1	2	2	2	2	2	1	2	2	2	1	2	2
23	3	1	2	2	2	2	2	1	2	2	2	2	2	2
24	3	1	1	1	2	2	2	2	2	2	2	2	2	2
25	3	1	2	2	2	2	2	2	2	2	2	2	2	2
26	1	3	2	2	1	2	2	1	2	2	2	2	1	2
27	4	1	2	2	2	2	2	2	2	2	2	2	2	2
28	1	1	2	2	2	2	2	2	2	2	2	2	2	2
29	4	1	2	2	2	2	2	2	2	2	2	2	2	2
30	4	1	2	2	2	2	2	2	2	2	2	2	2	2
31	4	1	2	1	2	2	2	2	2	2	2	2	1	2
32	4	0	2	2	2	2	2	2	2	2	2	2	1	2
33	4	0	1	2	2	2	2	2	2	2	2	2	2	2
34	4	3	1	2	1	2	2	1	2	2	2	2	2	2
35	3	1	1	1	2	2	1	1	2	1	2	2	1	1
36	4	2	2	2	2	2	2	2	2	2	2	2	2	2
37	3	1	2	2	2	2	2	2	2	2	2	2	2	2
38	3	1	2	2	2	2	2	2	2	2	2	2	1	2
39	4	1	2	2	2	2	2	2	2	2	2	2	2	2
40	2	1	1	1	2	2	1	2	2	2	2	2	2	2

Serial No	ANY HISTORY OF BRAIN SURGERY	DOES ANY FAMILY MEMBER HAVE A HISTORY OF SEIZURE OR EPILEPSY	IF YES RELATION	CONSANGUINEOUS PARENTS	ANY OTHER SIGNIFICANT HISTORY	NUMBER OF HOURS OF SLEEP IN DAY	NUMBER OF HOURS OF SLEEP AT NIGHT	SLEEPING AREA	DIET	ALCOHOL DURING TREATMENT PERIOD	SMOKING DURING TREATMENT PERIOD	ANY OTHER SUBSTANCE ABUSE	Any susbtance abuse	HEALTH INSURANCE	AGE AT MENARCHE	Last Menstrual Period
1	2	2	0	2	0	0	9	3	2	2	1	1	1	3	0	0
2	2	2	0	2	0	0	12	3	3	1	1	1	2	3	0	0
3	2	2	0	2	0	0	9	3	1	1	1	1	2	3	0	0
4	2	2	0	2	0	0	8	3	2	1	1	1	2	1	13	1/9/2021
5	2	2	0	2	0	2	9	3	1	1	1	1	2	3	14	9YEARS AGO
6	2	2	0	2	0	0	6	3	1	1	1	4	1	3	0	0
7	2	2	0	2	0	0	7	3	2	1	1	1	2	2	0	0
8	2	2	0	2	0	1	7	2	1	1	1	1	2	1	17	2/23/2020
9	2	2	0	2	0	1	6	3	2	1	1	1	2	3	12	5/7/2021
10	2	2	0	2	0	0	10	1	1	2	1	2	1	1	0	0
11	2	1	1	0	0	0	0	0	1	1	1	1	2	1	0	0
12	2	2	0	2	0	0	9	3	2	1	1	1	2	1	0	0
13	2	2	0	2	0	2	10	2	1	1	1	1	2	1	0	0
14	2	2	0	2	0	0	10	3	1	1	1	1	2	1	16	2/28/2021
15	2	2	0	2	0	2	7	3	1	1	1	1	2	1	15	2/23/2021
16	2	1	3	0	0	0	9	3	1	1	1	1	2	1	12	2016
17	2	2	0	2	0	2	6	2	1	1	1	1	2	1	15	2021
18	2	2	0	2	0	1	6	3	1	1	1	1	2	1	15	2021
19	2	2	0	2	0	2	6	3	2	1	1	1	2	1	0	0
20	2	2	0	2	0	1	7	2	2	1	1	1	2	1	12	2/12/2021
21	2	2	0	2	0	1	9	3	1	1	1	1	2	1	0	0
22	2	1	2	2	0	0	12	3	1	1	1	1	2	3	0	0
23	2	2	0	2	0	0	10	1	1	1	1	1	2	3	0	0
24	2	2	0	2	0	2	9	3	1	1	1	1	2	1	0	0
25	2	2	0	2	0	0	8	2	1	1	1	1	2	1	0	0
26	2	1	2	2	0	0	6	1	2	1	1	1	2	1	0	0
27	2	2	0	2	0	1	7	3	1	1	1	1	2	1	13	4/26/2021
28	2	2	0	2	0	0	7	3	1	1	1	1	2	1	0	0
29	2	1	2	2	0	1	8	3	2	1	1	1	2	1	13	5/14/2021
30	2	2	0	2	0	0	10	3	1	1	1	1	2	1	0	0
31	2	2	0	2	0	0	9	3	3	3	2	3	1	1	0	0
32	2	2	0	2	0	0	10	3	2	1	2	1	1	1	0	0
33	2	2	0	2	0	2	7	3	1	1	1	1	2	1	15	2019
34	2	2	0	2	0	1	8	3	2	1	1	1	2	1	0	0
35	2	2	0	2	0	1	9	3	1	1	1	1	2	1	0	0
36	2	2	0	2	0	0	4	3	1	1	1	1	2	1	18	2019
37	2	2	0	2	0	1	5	1	1	1	1	1	2	1	14	2021
38	2	2	0	2	0	0	9	3	2	1	1	1	2	3	0	0
39	2	1	3	2	0	1	7	3	1	1	1	1	2	1	16	2/7/2021
40	2	2	0	2	0	0	3	3	2	1	1	4	1	2	0	0

Serial No	DURATION IN DAYS	FLOW	REGULARITY	DOES SEIZURE OCCUR JUST BEFORE AFTER OR NO RELATION WITH MENSES	NUMBER OF PREGNANCY	NUMBER OF MISCARRIAGE	NUMBER OF LIVE BIRTH	HISTORY OF BIRTH DEFECT IN CHILDREN	ANY CHILD WITH EPILEPSY	REMARKS	WEIGHT IN KILOGRAM	HEIGHT IN METER	BMI IN KG PER METER SQUARE	SBP IN MMHG	DBP IN MMHG	PULSE PER MINUTE	Treatment gap
1	0	0	0	0	0	0	0	0	0	0	80	1.6	31.3	136	86	90	1
2	0	0	0	0	0	0	0	0	0	0	23	1.2	16.0	0	0	0	2
3	0	0	0	0	0	0	0	0	0	0	76	1.7	26.3	132	86	88	1
4	3	1	1	2	0	0	0	2	2	0	38	1.5	16.9	90	60	66	2
5	3	1	1	0	6	0	6	2	2	0	80	1.6	31.3	140	90	100	2
6	0	0	0	0	0	0	0	0	0	0	60	1.7	20.8	0	0	0	2
7	0	0	0	0	0	0	0	0	0	0	50	1.7	17.3	106	78	84	2
8	3	1	1	2	0	0	0	0	0	0	40	1.5	17.8	90	60	88	1
9	2	1	1	2	2	0	2	2	2	0	72	1.7	24.9	150	92	100	1
10	0	0	0	0	0	0	0	0	0	0	66	1.8	20.4	100	72	88	1
11	0	0	0	0	0	0	0	0	0	0	20	1.1	16.5	0	0	0	2
12	0	0	0	0	0	0	0	0	0	0	13	0.9	16.0	0	0	0	2
13	0	0	0	0	0	0	0	0	0	0	60	5.3	2.1	90	60	96	1
14	4	1	1	2	6	0	6	2	2	0	55	1.5	24.4	130	84	78	2
15	3	1	1	0	0	0	0	0	0	0	50	1.6	19.5	118	80	84	2
16	3	1	1	2	3	0	3	2	2	0	75	1.7	26.0	148	86	92	1
17	2	1	1	2	0	0	0	0	0	0	60	1.5	26.7	128	76	84	2
18	2	1	1	2	0	0	0	0	0	0	46	1.5	20.4	118	76	88	1
19	0	0	0	0	0	0	0	0	0	0	19	0.9	23.4	0	0	0	1
20	3	1	1	2	0	0	0	0	0	0	38	1.5	16.8	90	60	88	2
21	0	0	0	0	0	0	0	0	0	0	45	1.7	18.9	0	0	0	1
22	0	0	0	0	0	0	0	0	0	0	56	1.3	33.1	100	70	80	2
23	0	0	0	0	0	0	0	0	0	0	65	1.8	20.1	0	0	0	2
24	0	0	0	0	0	0	0	0	0	0	11.5	0.9	14.2	0	0	0	2
25	0	0	0	0	0	0	0	0	0	0	55	1.5	24.4	130	84	70	2
26	0	0	0	0	0	0	0	0	0	0	72	1.6	28.1	0	0	0	2
27	3	1	1	2	2	1	2	2	2	0	47	1.6	18.4	100	74	88	1
28	0	0	0	0	0	0	0	0	0	0	67	1.7	23.2	112	82	96	2
29	3	1	1	2	1	4	1	2	2	0	60	1.5	26.7	116	74	84	1
30	0	0	0	0	0	0	0	0	0	0	50	1.6	20.3	110	80	78	1
31	0	0	0	0	0	0	0	0	0	0	50	1.6	21.1	136	84	88	1
32	0	0	0	0	0	0	0	0	0	0	54	1.7	18.6	136	88	96	1
33	2	1	1	2	0	0	0	0	0	0	68	1.5	30.2	146	84	88	2
34	0	0	0	0	0	0	0	0	0	0	50	1.5	22.2	0	0	0	1
35	0	0	0	0	0	0	0	0	0	0	14	1.1	11.6	0	0	0	1
36	3	1	1	2	5	0	5	0	2	0	44	1.7	15.2	140	90	92	1
37	3	1	1	0	0	0	0	0	0	0	55	1.6	21.5	124	88	88	1
38	0	0	0	0	0	0	0	0	0	0	70	1.7	24.2	100	70	86	2
39	4	0	1	2	2	0	2	2	2	0	82	1.6	32.0	144	86	92	1
40	0	0	0	0	0	0	0	0	0	0	56	1.7	19.3	130	74	92	1

Serial No	can subject answer for himself	if no who will	NAME	AGE	Gender	Village	YOS	RELIGION	CASTE	Marital status	LIVING with	TYPE OF FAMILY	WORKING	IF WORKING	IF PREVIOUSLY WORKING	INCOME IN RUPEE PER MONTH	ETHNICITY	SESS MUP SCORE	SESS MUP GRADE	DURATION SINCE FIRST SEIZURE IN MONTHS
41	1	0	GK	24	2	12	4	2	1	1	3	2	4	0	0	8500	1	16	4	288.0
42	1	0	HS	37	1	12	10	2	1	1	2	1	1	2	0	7000	1	22	4	84.0
43	2	1	SS	8	1	12	2	2	2	1	3	2	1	5	0	6000	1	21	4	36.0
44	1	0	SS	35	1	12	10	2	1	4	3,4	2	1	4	0	4000	1	19	4	348.0
45	1	0	CS	70	1	13	8	2	2	5	2	2	3	0	1	20,000	1	36	2	540.0
46	2	2	GS	16	1	13	2	2	2	1	3	2	2	0	0	20000	1	22	4	190.0
47	1	0	JK	18	2	13	12	2	1	1	3	2	3	5	1	25000	1	25	3	96.0
48	1	0	KK	35	2	13	0	2	2	5	2,4	2	4	0	0	20,000	1	22	4	312.0
49	1	0	L	21	1	13	8	2	2	1	3	2	1	3	0	16000	1	25	3	252.0
50	2	1	NK	27	2	13	0	2	2	1	3	1	2	0	1	5000	1	22	4	18.0
51	2	1	NS	6	1	13	0	2	1	1	3	2	2	0	0	7500	1	16	4	72.0
52	1	0	BS	48	1	13	10	2	2	5	2	1	1	1	0	20000	1	34	2	48.0
53	2	1	DS	8	1	14	5	1	2	1	3	2	1	5	0	10,000	1	26	3	96.0
54	1	0	SK	30	2	14	5	2	2	5	2	1	4	0	0	12500	1	26	3	24.0
55	2	3	BK	64	2	14	10	2	2	5	2	1	4	0	0	10000	1	25	3	4.0
56	1	0	GS	42	1	14	0	2	2	1	3	2	1	1	0	22000	1	25	3	504.0
57	1	0	MS	65	1	15	8	2	2	5	2	1	3	0	1	1000	1	22	4	336.0
58	1	0	S	15	1	15	6	2	1	1	3	2	1	5	0	5000	1	23	4	180.0
59	2	1	TS	12	1	15	0	2	2	1	3	2	2	0	0	10,000	1	28	3	153.0
60	1	0	TK	81	2	15	0	2	2	2	4	2	2	0	0	10000	1	22	4	36.0
61	1	0	VS	34	1	15	8	2	1	5	2	2	1	2	0	15000	1	23	4	60.0

Serial No	Duration since first seizure grading	WHOM DID YOU CONTACT AT THAT TIME	DURATION SINCE LAST SEIZURE IN MONTHS	WHOM DID YOU CONTACT AT THAT TIME	CURRENT FREQUENCY OF DOMINANT SEIZURES	DESCRIPTION OF PRIOR SEIZURE	WAS THE TREATMENT STARTED	When was the treatment sought after first seizure	TYPE OF ANTIEPILEPTIC TREATMENT	HOW DID YOU FEEL AFTER STARTING TREATMENT	NUMBER OF DIFFERENT AED PRESCRIBED FOR EPILEPSY	IN A DAY HOW MANY TIMES DO YOU HAVE TO TAKE EACH MEDICINE FOR EPILEPSY	CAN YOU NAME YOUR MEDICINE	IF YES THEN NAME	ARE YOU CURRENTLY ON TREATMENT WITH AED	IF NO DID YOU STOP MEDICINE ON ADVICE OF YOUR DOCTOR
41	3	2	1.0	2	2	3	2	2	2	4	0	0	0	0	0	0
42	2	2	1.0	3	1	6	1	1	1	3	2	2	1	2,3	1	0
43	1	1	6.0	1	2	3,4	1	1	1	1	2	2	2	0	1	0
44	3	3	12.0	2	2	5	1	1	2	3	1	2	1	3	1	0
45	3	1	24.0	3	2	1,2	1	2	2	1	1	2	2	0	2	2
46	3	1	8.0	1	2	4,6	1	1	1	2	2	2	2	0	1	0
47	2	1	21.0	1	1	1	1	1	1	2	2	2	1	2,4,5	1	0
48	3	3	4.0	2	2	1	1	1	2	3	1	2	2	0	1	0
49	3	3	108.0	2	1	3	1	1	2	2	2	2	1	2,9	1	0
50	1	2	3.0	2	2	8	1	2	1	3	2	2	2	0	1	0
51	2	2	0.0	2	1	1	1	2	1	1	1	1	2	0	1	0
52	1	2	24.0	2	2	1,2,4	1	1	1	1	1	2	2	0	2	2
53	2	1	36.0	1	2	3	1	1	1	1	2	2	1	4,7	1	0
54	1	2	7.0	2	2	2	1	1	1	3	1	1	1	7	1	0
55	1	2	4.0	2	2	7	1	1	1	3	1	2	1	4	1	0
56	3	1	1.0	1	2	6	1	2	2	3	2	2	2	0	1	0
57	3	2	12.0	2	1	5	1	1	1	3	1	2	2	0	1	0
58	3	2	60.0	1	1	1	1	1	1	1	2	2	2	0	1	0
59	3	2	6.0	2	2	4	1	1	1	3	1	2	1	7	1	0
60	1	0	36.0	3	1	7	2	0	0	0	0	0	0	0	0	0
61	1	3	1.0	3	2	1	1	1	2	2	2	2	2	0	2	2

Serial No	IF NO TO PREVIOUS QUESTION WHY DID YOU STOP THE TREATMENT	SPECIFY SIDE EFFECT IF PRESENT	DO YOU FORGET TO TAKE SEIZURE MEDICATION SOMETIME	DO YOU SOMETIMES SKIP YOUR MEDICATION	IF YES REASON FOR SKIPPING THE MEDICINE	SPECIFY SIDE EFFECT IF PRESENT	FROM WHERE DO YOU TAKE MEDICATION	IS MEDICINE ALWAYS AVAILABLE	IF MEDICINE IS NOT ALWAYS AVAILABLE AT REGULAR SOURCE	IS DOCTOR ALWAYS AVAILABLE WHEN YOU GO TO HEALTH FACILITY	DISTANCE OF HEALTH FACILITY FROM YOUR HOUSE IN NEAREST KILOMETER	GRADING OF DISTANCE OF HEALTH FACILITY FROM YOUR HOUSE IN NEAREST KILOMETER	MODE OF TRANSPORT	HOW MUCH TIME DOES IT TAKE TO TRAVEL TO HEALTH FACILITY FROM YOUR HOME IN HOURS
41	0	0	0	0	0	0	0	0	0	0	0	0	0	0
42	0	0	2	2	0	0	8,5	1	0	2	7	2	1	30
43	0	0	2	2	0	0	9	1	0	1	25	3	1	30
44	0	0	2	2	0	0	9	1	0	1	28	3	1	40
45	6	0	1	1	6	0	1,4,8,5,6	1	0	1	30	3	1	45
46	0	0	2	2	0	0	9	1	0	1	120	3	3	180
47	0	0	2	2	0	0	7,8,6	1	0	1	30	3	1	90
48	0	0	2	2	0	0	4	2	2	2	1	1	1	15
49	0	0	2	2	0	0	8,6	1	0	1	20	3	1	35
50	0	0	2	1	7	8	8	1	0	1	25	3	1	40
51	0	0	2	2	0	0	7	1	0	1	5	1	1	30
52	2,5	0	2	1	14,12	0	8	1	0	1	10	2	1	15
53	0	0	2	2	0	0	9	1	0	1	30	3	2	60
54	0	0	1	1	11,13,14	0	8	1	0	1	7	2	3	30
55	0	0	2	2	0	0	8	1	0	1	30	3	3	50
56	0	0	2	1	3	0	7,9	1	0	1	40	3	1	60
57	0	0	2	2	0	0	8	1	0	1	22	3	1	60
58	0	0	2	2	0	0	1,7,8,9	1	0	1	90	3	1,3	120
59	0	0	2	2	0	0	9,6	1	0	1	10	2	1	60
60	0	0	0	0	0	0	0	0	0	0	0	0	0	0
61	7	1,2,3,4	1	2	7	1,2,3,4	7,8,9	1	0	1	6	2	1	15

Serial No	DOES THIS DISTANCE TO HEALTH FACILITY KEEP YOU FROM REFILLING YOUR MEDICIATION	DO YOU HAVE DIFFICULTY IN TRAVELING TO HEALTH FACILITY	WHO ACCOMPANIES YOU	WERE YOU COUNSELLED BY HEALTH CARE PERSONNEL DOCTOR ON NEED OF REGULAR MEDICATION USE AND CONSEQUENCES OF NON ADHERENCE	treatment gap	WERE YOU REFFERED FROM ONE CENTRE TO OTHER	IF YES DID YOU FOLLOW UP AT THE REFERRED CENTRE	IF YOU DID NOT FOLLOW UP THEN WHY	DOES ATTITUDE OF HCP TOWARDS YOUR ILLNESS KEEP YOU FROM GOING TO CLINIC	ARE YOU SATISFIED WITH THE QUALITY OF MEDICAL CARE AT THE HEALTH FACILITY	FOR HOW MUCH PERIOD DRUGS ARE DISPENSED AT ONE TIME	FOR HOW LONG DO YOU HAVE TO WAIT AT HOSPITAL	HAVE YOU EVER HEARD OF EPILEPSY BEFORE	IS EPILEPSY A
41	0	0	0	0	1	0	0	0	0	0	0	0	2	1
42	2	2	4	2	2	2	0	0	2	1	2	1	2	2
43	2	2	3	1	2	2	0	0	2	1	2	2	2	4
44	2	2	3	1	2	2	0	0	2	1	2	2	1	1
45	2	2	6	2	1	2	2	1	2	2	1	2	1	1
46	2	1	3	1	2	2	0	0	2	1	2	2	2	1
47	2	2	2	1	2	2	2	1	2	1	2	2	1	2
48	2	2	1	2	1	2	0	0	2	1	1	2	2	1
49	2	2	0	1	2	2	0	0	2	2	2	2	2	4
50	2	1	2,8	2	1	2	0	0	2	1	1	2	2	4
51	2	2	2,3	1	2	2	0	0	2	1	1	2	2	1
52	2	1	6	2	1	2	0	0	2	1	1	2	1	1
53	2	2	2,3	1	2	2	0	0	2	1	1	2	2	1
54	1	1	0	2	1	2	0	0	2	1	1	2	1	4
55	1	1	6	1	2	2	0	0	2	1	1	2	1	4
56	2	2	3,4	2	1	2	0	0	2	1	2	2	2	4
57	2	1	1	1	2	2	0	0	2	1	2	1	2	4
58	2	1	3	1	2	2	0	0	2	1	2	2	2	4
59	1	1	3	1	2	1	1	0	2	1	2	1	2	4
60	0	0	0	0	1	0	0	0	0	0	0	0	2	4
61	1	1	1,6	2	1	2	0	0	1	2	1	1	2	4

Serial No	WHAT DO YOU THINK EPILEPSY IS CAUSED BY	DO YOU BELIEVE THAT MEDICINE AED PRESCRIBED NOW WILL CONTROL YOUR EPILEPSY	ANY COMORBID CONDITIONS	CONCOMITANT MEDICATION	ANY HISTORY OF FEVER	ANY HISTORY OF HEADACHE	ANY HISTORY OF FOCAL NEUROLOGICAL DEFICIT	ANY HISTORY OF FEBRILE SEIZURES IN CHILDHOOD	ANY HISTORY OF CHILDHOOD ENCEPHALOPATHY	ANY HISTORY OF NEONATAL HYPOGLYCEMIA	ANY HISTORY OF KERNICTERUS	ANY HISTORY OF SIGNIFICANT BIRTH HISTORY	ANY HISTORY OF HEAD INJURY	ANY HISTORY OF CNS INFECTION
41	4	0	2	2	2	2	2	2	2	2	2	1	2	2
42	4	1	2	2	2	2	2	2	2	2	2	2	2	2
43	4	1	2	2	2	2	2	2	2	2	2	2	2	2
44	2,4	1	2	2	2	2	2	2	2	2	2	2	2	2
45	1	1	2	2	2	2	2	2	2	2	2	2	2	2
46	4	0	1	2	2	2	1	2	2	2	2	2	2	2
47	3	1	1	2	2	2	2	2	2	2	2	2	2	2
48	3	1	2	2	2	2	2	1	2	2	2	1	2	2
49	4	2	2	2	2	2	1	2	2	2	2	2	2	2
50	4	1	1	2	2	2	1	2	2	2	2	2	2	2
51	4,1	1	2	2	2	1	1	2	2	2	2	1	2	2
52	4	1	2	2	2	2	2	2	2	2	2	2	2	2
53	4	1	2	2	2	2	2	2	2	2	2	2	2	2
54	3	1	2	2	2	2	2	2	2	2	2	2	2	2
55	3	1	1	1	2	2	1	2	2	2	2	2	2	2
56	4	1	2	2	2	2	2	2	2	2	2	2	2	2
57	4	1	2	2	2	2	2	2	2	2	2	2	2	2
58	4	1	2	2	2	2	2	2	2	2	2	2	2	2
59	5	1	2	2	2	2	1	1	2	2	2	1	2	2
60	4	0	1	2	2	2	1	2	2	2	2	2	2	2
61	4	3	2	2	2	1	2	2	2	2	2	2	2	2

Serial No	ANY HISTORY OF BRAIN SURGERY	DOES ANY FAMILY MEMBER HAVE A HISTORY OF SEIZURE OR EPILEPSY	IF YES RELATION	CONSANG UINEOUS PARENTS	ANY OTHER SIGNIFICANT HISTORY	NUMBER OF HOURS OF SLEEP IN DAY	NUMBER OF HOURS OF SLEEP AT NIGHT	SLEEPING AREA	DIET	ALCOHOL DURING TREATMENT PERIOD	SMOKING DURING TREATMENT PERIOD	ANY OTHER SUBSTANCE ABUSE	Any susbtance abuse	HEALTH INSURANCE	AGE AT MENARCHE	Last Menstrual Period
41	2	1	3	2	0	1	10	2	1	1	1	1	2	1	15	2021
42	2	2	0	2	0	0	10	3	2	1	1	1	2	1	0	0
43	2	2	0	2	0	0	8	3	1	1	1	1	2	1	0	0
44	2	2	0	2	0	0	9	3	1	1	1	1	2	1	0	0
45	2	2	0	2	0	0	10	3	2	3	1	1	1	1	0	0
46	2	1	1	2	0	2	7	2	1	1	1	1	2	1	0	0
47	2	1	3	2	0	0	9	3	1	1	1	1	2	1	12	2/6/2021
48	2	2	0	2	0	1	6	3	1	1	1	1	2	1	15	2/11/2021
49	2	1	3	2	0	0	9	3	1	1	1	1	2	1	0	0
50	2	2	0	2	0	2	7	3	1	1	1	1	2	1	12	1/31/2021
51	2	2	0	2	0	0	5	3	1	1	1	1	2	1	0	0
52	2	2	0	2	0	1	6	2	1	1	1	1	2	1	0	0
53	2	2	0	2	0	2	6	3	1	1	1	1	2	1	0	0
54	2	2	0	2	0	1	6	2	1	1	1	1	2	1	15	2021
55	2	2	0	2	0	2	5	2	1	1	1	1	2	1	13	2003
56	2	2	0	2	0	0	10	2	1	1	1	1	2	1	0	0
57	2	2	0	2	0	0	7	3	1	1	1	1	2	3	0	0
58	2	2	0	2	0	3	9	2	1	1	1	1	2	3	0	0
59	2	2	0	2	0	0	8	3	1	1	1	1	2	1	0	0
60	2	2	0	2	0	2	8	2	1	1	1	1	2	1	14	1988
61	2	2	0	2	0	0	10	3	1	2	1	3	1	1	0	0

Serial No	DURATION IN DAYS	FLOW	REGULARITY	DOES SEIZURE OCCUR JUST BEFORE AFTER OR NO RELATION WITH MENSES	NUMBER OF PREGNANCY	NUMBER OF MISCARRIAGE	NUMBER OF LIVE BIRTH	HISTORY OF BIRTH DEFECT IN CHILDREN	ANY CHILD WITH EPILEPSY	REMARKS	WEIGHT IN KILOGRAM	HEIGHT IN METER	BMI IN KG PER METER SQUARE	SBP IN MMHG	DBP IN MMHG	PULSE PER MINUTE	Treatment gap
41	4	1	2	0	0	0	0	0	0	0	61	1.5	27.1	124	78	88	1
42	0	0	0	0	0	0	0	0	0	0	68	1.7	23.5	110	78	84	2
43	0	0	0	0	0	0	0	0	0	0	20	1.3	12.8	0	0	0	2
44	0	0	0	0	0	0	0	0	0	0	42	1.5	18.2	130	88	84	2
45	0	0	0	0	0	0	0	0	0	0	50	1.7	17.3	120	80	84	1
46	0	0	0	0	0	0	0	0	0	0	63.5	1.8	19.6	96	62	88	2
47	2	1	1	1	0	0	0	0	0	0	75	1.6	29.3	122	86	84	2
48	4	1	1	2	3	0	3	2	1	0	47	1.6	18.4	128	90	84	1
49	0	0	0	0	0	0	0	0	0	0	60	1.6	23.4	110	70	84	2
50	1	1	2	2	1	0	0	2	2	0	50	1.4	25.5	0	0	0	1
51	0	0	0	0	0	0	0	0	0	0	13	1.0	13.0	0	0	0	2
52	0	0	0	0	0	0	0	0	0	0	70	1.5	31.1	112	88	84	1
53	0	0	0	0	0	0	0	0	0	0	22	1.1	18.2	0	0	0	2
54	3	1	1	2	1	0	1	0	0	0	62	1.5	27.6	110	80	88	1
55	4	1	1	2	2	0	2	0	0	0	65	1.6	25.4	104	78	84	2
56	0	0	0	0	0	0	0	0	0	0	70	1.7	25.7	120	78	88	1
57	0	0	0	0	0	0	0	0	0	0	70	1.8	22.1	108	90	96	2
58	0	0	0	0	0	0	0	0	0	0	40	1.5	17.8	90	60	86	2
59	0	0	0	0	0	0	0	0	0	0	30	1.1	24.8	0	0	0	2
60	3	1	1	2	0	0	0	0	0	0	80	1.5	35.6	150	88	106	1
61	0	0	0	0	0	0	0	0	0	0	100	1.7	34.6	134	88	96	1

PREVALENCE OF EPILEPSY AND DETERMINANTS OF TREATMENT GAP IN PEOPLE WITH EPILEPSY IN RURAL LUDHIANA

THESIS PROPOSAL

FOR APPROVAL OF SUBJECT OF THESIS TO BE SUBMITTED

IN PARTIAL FULFILMENT OF THE REQUIREMENTS

FOR THE DEGREE OF

Doctor of Medicine

in

COMMUNITY MEDICINE

OF THE

BABA FARID UNIVERSITY OF HEALTH SCIENCES
FARIDKOT

NOVEMBER 2019

Dr. Aman Bansal

DEPARTMENT OF COMMUNITY MEDICINE
DAYANAND MEDICAL COLLEGE AND HOSPITAL
LUDHIANA

ABSTRACT OF PLAN OF THESIS

Title	PREVALENCE OF EPILEPSY AND DETERMINANTS OF TREATMENT GAP IN PEOPLE WITH EPILEPSY IN RURAL LUDHIANA
For the degree of	M.D. Community Medicine
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Introduction: Epilepsy poses enormous social and economical burden among low and middle income countries. It is one of the most common neurological condition which accounts for more than 0.5% of the global disease burden affecting nearly 50 million people worldwide. According to WHO estimated prevalence of epilepsy in India varies from 3.6 to 7 per 1000 people.

Aim of Study: To find prevalence of epilepsy and to study the determinants of treatment gap in people with epilepsy in rural Ludhiana.

Materials & methods: This is a community based cross-sectional study. It will be carried out in the field practice area of Rural Health Training Centre (RHTC) located at village Pohir, Block Dehlon, District Ludhiana. It is composed of 15 villages having total population of 31043 people.

Clinical Significance: To identify factors affecting epilepsy treatment gap.

Keywords: Epilepsy, treatment gap, prevalence

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Candidate	Co-supervisor	Co-supervisor	Supervisor	Principal

CERTIFICATE OF FACILITIES AVAILABLE

This is to certify that the facilities for work on the subject of thesis titled **"PREVALENCE OF EPILEPSY AND DETERMINANTS OF TREATMENT GAP IN PEOPLE WITH EPILEPSY IN RURAL LUDHIANA"** exist in the Department of Community Medicine, Dayanand Medical College and Hospital, Ludhiana and will be provided to the candidate. We will see that the data being included in the thesis are genuine and is collected by the candidate himself/herself under our supervision and guidance.

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4	DATE OF ADMISSION OF COURSE	13th May 2019
5	TITLE OF THE TOPIC	Prevalence of epilepsy and determinants of treatment gap in people with epilepsy in rural Ludhiana.

6. BRIEF RESUME OF THE INTENDED WORK

6.1 NEED FOR THE STUDY

Globally mental, neurological and substance use (MNS) conditions impose an enormous public health problem that leads to premature mortality and affects the quality of life. MNS conditions (e.g. depression, psychoses, epilepsy, dementia, disorders due to substance abuse) represent approximately 14% of the global disease burden.[1]

India is passing through a phase of epidemiological transition with an increasing burden of non-communicable diseases (NCD) consequent to the improvement of health care services in preventive and curative domains. [2] Neurological disorders form a major proportion among the NCDs. Epilepsy is one of the most common neurological diseases.

Historically epilepsy was first mentioned by the Greeks as "Epilepsia" which means to seize. One of oldest account of epilepsy is found on a Babylonian tablet from 2000 B.C. which emphasizes on supernatural nature of the disease. In *Corpus Hippocraticum* from 400 B.C., Hippocrates didn't believe that epilepsy is a sacred disease which was in contrast to previously held beliefs of it being due to mystical causes. *Charak Samhita*, ancient text in Indian system of medicine, gives a detailed description of epilepsy as "*aphasmara*" to be treated as physical disease and is known as "*mirgi*" in Hindi. In the modern era, epilepsy was described as brain disorder by *J.H.Jackson*, a British neurologist in the year 1873.

Epilepsy has been defined as a brain disease with at least two seizures occurring in the absence of precipitating factor more than 24 hours apart. [3] Epilepsy can occur in any age group, both male and female, all races, people of any socio-economic status. Cases of epilepsy are expected to rise with an increase in life expectancy.

In spite of its enormous social and economic burden globally, epilepsy is often ignored public health problem especially among low and middle-income countries (LMIC). People with epilepsy (PWE) as well as their families have to bear stigmatization, which limits social

inclusion, employment opportunities and interferes with health-seeking behaviour.

Epilepsy accounts for more than 0.5% of the global disease burden affecting nearly 50 million people worldwide. [4] A further 500 million people including families and carers of people with epilepsy (PWE) thought to be indirectly affected by this disease. [5] About 80% of PWE live in low- and middle-income countries (LMIC). [4] Furthermore, 75% of PWE in LMIC do not get appropriate treatment. [6]

According to WHO, the estimated prevalence of epilepsy in India varies from 3.6 to 7 per 1000, [6] it comprises about one-fifth of the global burden. Out of the limited number of studies conducted on epilepsy in Punjab, a study conducted in rural Patiala showed the prevalence of epilepsy to be 7.67 per 1000 people while the prevalence of epilepsy among 1-18 year came out to be 6.24/1000 population in Chandigarh.[7,8]

Epilepsy is usually a treatable condition. Epilepsy treatment gap includes undiagnosed cases of epilepsy and PWE not receiving treatment or receiving traditional medicine. [5] Epilepsy treatment gap exceeds 75% in most low- income countries and 50% in most middle-income countries. [9] The magnitude of the epilepsy treatment gap in India ranges from 40% in rural Rajasthan, 90% rural West Bengal and 22% in urban Mumbai [10-12]. A study in 1-18 years of age group showed the treatment gap of 22.2% in Chandigarh. [8] Up to 70% of PWE can remain seizure-free with the help of cost-effective anti-seizure medications, Hence, improving their quality of life and participation in society.[4]

To meet the target 3.8 of Sustainable Development Goals (SDG) globally, prevention, treatment and care for MNS conditions must be integrated into public health services. In 68th World Health Assembly (WHA) in 2015 resolution on epilepsy was adopted unanimously by member states including India. [13] In 2018 political declaration was made to include mental and neurological disease under the umbrella of NCD by High Level Meeting of UN general assembly.[14]

The problem of the treatment gap in epilepsy is magnified by the stigma and negative attitudes attached to it. Consequently, many of them are forced to live without appropriate treatment despite an effective treatment being available. There is a scarcity of knowledge on the determinants of treatment gap in PWE which is a hindrance in adequate utilization of health services available. In the light of above discussion, this community-based study is planned to estimate the prevalence, treatment gap in and its determinants in PWE.

6.2 REVIEW OF LITERATURE

Epilepsy is an age-old disease. It's symptoms and different types are described on an important manuscript of Neo-Babylonian (626-539 BC) tablet of medical diagnostic series. This tablet is made of clay and dates back 1500 - 4000 years. It is currently located in the British Museum, London. Wilson *et al* in 1990, Stol *et al* in 1993, Nils *et al* in 2000 have translated text from this tablet, [15]

Worldwide, epilepsy imposes an enormous public health problem that leads to premature mortality and affects the quality of life. In low and middle-income countries, the excess mortality is associated with lack of access to health facilities. In spite of its enormous social and economic burden epilepsy is often ignored public health problem, especially among low and middle-income countries. Due to the epidemiological transition, developing countries are facing a double burden of communicable and non-communicable disease. However, non-communicable diseases are on the rise in our country.

Murray *et al* (2012) in a systematic analysis of Global Burden of Disease observed that there is a shift in the composition of Disability-adjusted life years (DALYs) although total DALY remained stable globally. Worldwide communicable, maternal, neonatal, and nutritional disorders combined contributed to 47% of DALY in 1990 which declined to 35% in 2010 while DALY due to non-communicable disease rose from 43% to 54% during the same period. Globally 3% of DALY's were due to neurological disorders and one-fourth of which were due to epilepsy which translates to 253 DALY per lakh population in 2010. [16]

In the year 2019, Global burden of disease 2016 Neurology collaborators, found that the absolute number of DALYs due to neurological disorders is increasing. As the population is ageing there will be a rise in the prevalence of major neurological disorders. With this, there will be an increase in demand for rehabilitative and support service from the public health sector. They found that epilepsy

contributed over 13.5 million DALY's which is a 9% increase since 1990. [17]

J.W.Sander in 2003 observed that Epilepsy causes a significant burden on individuals and the healthcare system. It is estimated nearly 50 million people suffer from epilepsy. Prevalence of epilepsy across the globe is estimated to be 5 – 10 per 1000 population. It can be more than 10 per 1000 in some places. Age-specific incidence rates have changed. There is an increase in prevalence in old age group and a decrease in young age group. [18]

Fiest *et al* (2016) published a systemic review and meta-analysis in the official journal of American Academy of Neurology in which lifetime prevalence of epilepsy was 7.6 per 1000 persons. There was no change in prevalence of epilepsy when sorted by age group, study quality or gender. The highest prevalence of epilepsy is of unknown aetiology. They pointed out the gap in various studies and called for standardization in reporting of future epidemiological studies on epilepsy. [19]

In epilepsy: a public health imperative (2019) World Health Organization estimates prevalence of epilepsy in India from 3.6 to 7 per 1000 taking into account the studies conducted from 1998 to 2014 from various parts of india.[6]

Pandey *et al* (2014) studied the prevalence of epilepsy in 1-18year age group in the union territory of Chandigarh by two-stage cluster sampling technique. Standard definitions provided by the international league against epilepsy were used to define cases and calculation of treatment gap in the community. The prevalence rate for epilepsy in 1-18year age group came out to be 6.24/1000 population and treatment gap was found to be 22.2% which was very low as compared with other studies from India. This low treatment gap was attributed to easily accessible health care facilities in and around the city by the author. [8]

Hara *et al* studied epilepsy in rural Patiala by the door to door survey in 2008 in which prevalence rate comes out to be 7.67/1000 which was similar to that of an urban area but less than prevalence rate of remote

rural area. For categorization of epilepsy this study mainly relied upon history and clinical examination. [7]

At least half of the people in the world do not receive the health services they need. To create awareness, World Health Organization has chosen World Health Day theme for the year 2018 and 2019 consecutively as "universal health coverage". Every aspect comprising of health promotion, prevention, treatment and palliative care should be available to everyone everywhere. We must improve the accessibility, safety and affordability of primary health care for the masses. Health workers have to educate patients at the community level on taking care of their health. [20]

Brodie et al (2012) reported treatment options for people with epilepsy has been available since the early 20th century. Moreover, 75% have treatable epilepsy and can lead near-normal lives on an appropriate regimen, yet 85% of people with epilepsy do not get appropriate treatment due to various reasons.[21]

Shorvon *et al* (1988) coined the term Epilepsy Treatment Gap. From initial observations in Ecuador, Pakistan and Philippines epilepsy treatment gap was observed to be more than 80 per cent. They advocated for using a screening questionnaire in a community for a more positive response as compared to clinical examination. During study community perceived causes of epilepsy as supernatural (will of God, visiting cemeteries, witchcraft), environmental (climate, phases of the moon), physical (bad behaviour, certain disease, brain damage) and psychological (guilt, worry, anger, tendency to think too much). [22]

Meinardi *et al* (2001) in ILAE Commission report on treatment gap in epilepsy defines the seizure treatment gap as 'The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given time, expressed as a percentage'. This definition includes diagnostic and therapeutic deficits. Beside defining treatment gap, measurement of treatment gap, its causes, and potential ways to reduce it are also elicited by the author. To provide indirect measure epilepsy treatment gap and people with epilepsy who are on medicine

two separate formula was described. To ameliorate the treatment gap political commitment for providing resources like essential drug supply, help to create awareness among community and to describe how intervention to close this gap makes economic sense, literacy, income generation program, patient's perceptions, social relationships in which patient is embedded and their cultural practices concerning epilepsy, education and training of health workers and full integration with community health delivery system are few factors described by author. [23]

According to the systematic review of 74 peer-reviewed publications done by Meyer *et al* in 2009, it has been estimated that epilepsy treatment gap exceeds 75 per cent in most low-income countries and 50 per cent in middle income and 10 per cent in high-income countries. It is more in rural areas as compared to urban areas. It revealed stark disparities both between and within countries in care of people with epilepsy. Epilepsy is a common neurological disorder with potentially serious health and social consequences if left untreated. Its diagnosis, effective and inexpensive treatment is available which can be prescribed by primary care physician. [9]

In both developed and developing countries, there is the negative public attitude towards epilepsy and political neglect of hidden and misunderstood disorder Three international agencies World Health Organization (WHO), International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) in 1997 jointly initiated Global Campaign Against Epilepsy . This collaboration is first of its kind in neurology. It is primarily for developing countries. Its mission is to improve availability, accessibility and acceptability of treatment modalities and preventive services as well. This initiative involves global, national and regional level inter-related activities.

Global Campaign Against Epilepsy proved to be a powerful tool for intervention in Epilepsy Treatment Gap (ETG). The ultimate goal of GCAE is to close ETG. According to 'bringing epilepsy out of shadows' campaign a lot of under-reporting of people with epilepsy in community settings was found which was due to stigmatization. In addition to that

various social issues also lead to fewer job opportunities which leads to emotional and financial hardships. The problem of the treatment gap in epilepsy is magnified by the stigma and negative attitudes attached to it. These factors play an important role in determining the adherence to treatment among people with epilepsy. [24]

At 68th World Health Assembly in 2015, a resolution on epilepsy was adopted calling for the "need for coordinated action at the country level' to address its health, social and public knowledge implications. In people with epilepsy risk for premature death are two times more in high-income countries and six times more in middle and low-income countries in comparison to the general population. World Health Organization and its key partners are drawing the attention of its member countries with the message of "The time to act is now" to address the burden of epilepsy through the public health system. Many steps to improve epilepsy care like strengthening effective leadership and governance, improving the provision of epilepsy care, increase access to medicine, increase public awareness and education and strengthening of health information and surveillance system are recommended. [13]

6.3 AIMS AND OBJECTIVES OF THE STUDY

1. To find prevalence of epilepsy in a rural area of Ludhiana.
2. To study the determinants of treatment gap in people with epilepsy.

7.MATERIALS AND METHODS

The present study "Prevalence of epilepsy and determinants of treatment gap in people with epilepsy in rural Ludhiana" is a community based cross-sectional study. The study will be carried out in the field practice area of Rural Health Training Centre (RHTC) located at village Pohir, Block Dehlon, District Ludhiana, Punjab, India. This centre is an integral part of Department of Community Medicine, Dayanand Medical College and Hospital, (DMC & H) Ludhiana. It comprises of 15 villages having a population of 31043 where home-based comprehensive health care is provided.

7.1 Source of Data

All Individuals residing in above mentioned rural area

7.2 METHOD OF COLLECTION OF DATA

INCLUSION CRITERIA

Whole of the population of the study area.

EXCLUSION CRITERIA

1. Non Co-operative subjects
2. Subjects who refuse to participate.

SAMPLE SIZE

The type of sampling used will be two step sampling.

First, Whole population of 15 villages under Rural Health Training Centre Pohir will be taken as sample for screening questionnaire to be administered.

Screened positive cases will be evaluated for diagnosis of epilepsy by Department of Neurology, DMC & H. Confirmed Epilepsy cases will form the second set of sample. They will be further studied in detail.

SAMPLING TECHNIQUE:

All households of these 15 villages will be visited door to door. Screening will be done in serial order. It will be done by investigator

with help of local multi-purpose health worker. Whole population residing is study area will be eligible for screening.

A 9-item screening questionnaire developed by Placencia in Ecuador [25] will be converted from English to Punjabi. This questionnaire has been previously validated for epidemiological studies of epilepsy in community. It will be administered to all members of family available at home at the time of visit by the investigator. For the members of household who are not at home at time of visit, questionnaire will be filled with help of senior most member available at home. If household is found locked during the period of study, two repeat visits will be done for screening, if it is found locked at the time of third visit also it will be excluded from the preview of screening.

Screened positive cases will be evaluated at RHTC Pohir by a team from Department of Neurology, DMC & H Ludhiana.

Subjects confirmed to have epilepsy will be taken up for further detailed study of their demographic profile, present / past medical history/ family/ personal history/ menstrual / obstetric history and questionnaire determining epilepsy treatment gap.

Operational definitions:

Active epilepsy: Defined by regular treatment with anti-seizure medicines or when the most recent seizure has occurred within the last 5 years. [26]

Lifetime prevalence: The risk of having epilepsy at some point during the lifetime; it is used to estimate the cumulative incidence of epilepsy.

Point prevalence: The number of cases of active epilepsy cases, divided by the target population on that day (active cases per 1000 persons).

Procedure of data collection

The aim of study will be explained to every subject and confidentiality of information will be assured. For those who will be screened positive and confirmed for epilepsy by neurological examination, further information (section 2-7) will be collected through a proforma by visiting house of person with epilepsy. The proforma is divided into following sections:

Section1. First, Placencia's 9 item screening questionnaire

Section 2. Socio-demographic profile

Section 3. Seizure History

Section 4. Treatment adherence

Section 5. Health care system availability and accessibility

Section 6. Awareness about epilepsy

Section 7. Medical and Surgical history

PILOT STUDY

It will be done on 30 subjects by randomly choosing the subjects to test the feasibility of the study.

STUDY INSTRUMENTS IN DETAIL

Section 1. Placencia's 9 item screening questionnaire

It was validated in Ecuador in 1992 for epidemiological studies of epilepsy in community. It contains 9 questions to be asked to a subject by investigator. It is divided into two sections. Both question 1 and 2 must be affirmative to render the subject positive AND/OR any question 3 to 9 if affirmative renders the subject positive.

Section 2. Socio demographic profile

This will include the details of subjects like name, age, gender, occupation, address and working or not, contact number, religion, caste and ethnicity. Socio economic assessment by Modified Udai Pareek Scale will allot following grading to households.[27]

Total score	Class	Socio-economic class grading
>43	Upper class	I
33-42	Upper middle class	II
24-32	Middle class	III
13-23	Lower middle class	IV
<13	Lower class	V

Section 3. Seizure history

Here duration since first and last seizure, frequency and pattern of current and prior seizures will be asked. Health seeking behavior of people with epilepsy, type of treatment taken, detailed treatment history with reasons of stoping treatment will be documented.

Section 4. Treatment adherence

We will determine reason for non- adherence of prescribed treatment among people with epilepsy who are put on treatment and are currently taking the anti-epileptic drugs.

Section 5. Healthcare system availability and accessibility

In this section, questions like type of health facility, availability of doctor, distance from health facility, mode of transport, person accompanying, duration for which medicines are dispensed, time patient have to spent at health facility will be asked.

Section 6. Awareness about epilepsy

The awareness about epilepsy will be determined among the people with epilepsy:

a) Who are diagnosed for the first time.
b) Who have not started treatment after being diagnosed previously.
c) Who have stopped treatment without doctor's advice.

Section 7. Medical and surgical history

It will include subsections. First subsection will be detailing co-morbidities and their concomitant treatments, past medical and surgical history will be asked. In second subsection will include family history regarding epilepsy and consanguineous marriage among parents of people with epilepsy. In third subsection sleeping pattern, diet, substance abuse and health insurance will be asked. In subsection four menstrual history, its relation to seizure, number of total conceptions, miscarriages and live children will be documented.

Section 8. General Physical Examination

Height, weight, blood pressure, body mass index of subject will be documented.

STUDY DURATION

The study will be conducted from 1st March 2020 to 28th February 2021

STATISTICAL ANALYSIS

Data will be described in terms of range; mean ±standard deviation (± SD), median, frequencies (number of cases) and relative frequencies

(percentages) as appropriate. Comparison of quantitative variables between the study groups will be done using ANOVA. For comparing categorical data, Chi square ($\chi 2$) test will be performed and exact test will be used when the expected frequency is less than 5. A probability value (p value) less than 0.05 will be considered statistically significant. All statistical calculations will be done using SPSS (Statistical Package for the Social Science) SPSS 21

7.3 DOES THE STUDY REQUIRE ANY INVESTIGATIONS OR INTERVENTIONS TO BE CONDUCTED ON PATIENTS OR OTHER HUMANS OR ANIMALS? IF SO, PLEASE DESCRIBE BRIEFLY.

No.

7.4 HAS ETHICAL CLEARANCE BEEN OBTAINED FROM YOUR INSTITUTION IN CASE OF 7.3?

Applied for.

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Annexure I--- Flowchart

1. Screening proforma.
2. Patient asked to come for neurological examination at RHTC.

a. Patient came for neurological examination

i. *Individuals diagnosed as non-epileptic on neurological examination—*

1. Proforma section
2. Socio-demographic profile

ii. *Individuals diagnosed as epileptic on neurological examination*

1. Diagnosed for first time
   a. Section 2- Socio-demographic profile
   b. Section 3- Seizure history
   c. Section 6- Awareness about epilepsy
   d. Section 7- Medical/ social/ family history.
2. Already diagnosed
   a. Completed treatment as per doctor advise
      i. Section 2- Socio-demographic profile
      ii. Section 3- Seizure history
      iii. Section 7- Medical/ social/ family history
   b. Taking AED
      i. Section 2- Socio-demographic profile
      ii. Section 3- Seizure history
      iii. Section 4- Treatment adherence
      iv. Section 5- Healthcare system availability and accessibility
      v. Section 7- Medical/ social/ family history
   c. Stopped AED after starting treatment
      i. Section 2- Socio-demographic profile
      ii. Section 3- Seizure history
      iii. Section 5- Healthcare system availability and accessibility

iv. Section 6- Awareness about epilepsy
v. Section 7- Medical/ social/ family history

d. Never took treatment

i. Section 2- Socio-demographic profile
ii. Section 3- Seizure history
iii. Section 5- Healthcare system availability and accessibility
iv. Section 6 - Awareness about epilepsy
v. Section 7- Medical/ social/ family history

e. Alternative medicine

i. Section 2- Socio-demographic profile
ii. Section 3- Seizure history
iii. Section 4- Treatment adherence
iv. Section 5- Healthcare system availability and accessibility
v. Section 6- Awareness about epilepsy
vi. Section 7- Medical/ social/ family history

b. Patient didn't come for neurological examination

i. <u>Not diagnosed before</u>

1. Needs evaluation

ii. <u>Already diagnosed</u>

a. Completed treatment as per doctor advise

i. Section 2- Socio-demographic profile
ii. Section 3- Seizure history
iii. Section 7- Medical/ social/ family history

b. Taking AED

i. Section 2- Socio-demographic profile
ii. Section 3- Seizure history
iii. Section 4- Treatment adherence
iv. Section 5- Healthcare system availability and accessibility
v. Section 7- Medical/ social/ family history

c. Stopped AED after starting treatment

i. Section 2- Socio-demographic profile
ii. Section 3- Seizure history
iii. Section 5- Healthcare system availability and accessibility
iv. Section 6- Awareness about epilepsy
v. Section 7- Medical/ social/ family history

d. Never took treatment

i. Section 2- Socio-demographic profile
ii. Section 3- Seizure history
iii. Section 5- Healthcare system availability and accessibility
iv. Section 6 - Awareness about epilepsy
v. Section 7- Medical/ social/ family history

e. Alternative medicine

i. Section 2- Socio-demographic profile
ii. Section 3- Seizure history
iii. Section 4- Treatment adherence
iv. Section 5- Healthcare system availability and accessibility
v. Section 6- Awareness about epilepsy
vi. Section 7- Medical/ social/ family history

PROFORMA

Section 1

Village		Household no.		S no.	
Name		Gender	Male/ Female	Age	years

Placencia's 9 item screening questionnaire

for the detection of epileptic seizures in epidemiological studies

1. Have you ever had attacks of shaking of the arms or legs which you could not control?
2. Have you ever had attacks in which you fall and become pale?

Both question 1 and 2 must be affirmative to render the subject positive.

3. Have you ever lost consciousness?
4. Have you ever had attacks in which you fall with loss of consciousness?
5. Have you ever had attacks in which you fall and bite your tongue?
6. Have you ever had attacks in which you fall and lose control of your bladder?
7. Have you ever had brief attacks of shaking or trembling in one arm or leg or in the face?
8. Have you ever had attacks in which you lose contact with the surroundings and experience abnormal smells?
9. Have you ever been told that you have or had epilepsy or epileptic fits?

Any question 3 to 9 if affirmative renders the subject positive.

Signature of Candidate **Signature of Supervisor**

Section 1A

Screening proforma in Punjabi

Village		Household no.		S no.	
Name		Gender	Male/ Female	Age	years

ਸਕ੍ਰੀਨਿੰਗ ਪ੍ਰਸ਼ਨਮਾਲਾ

1. ਕੀ ਤੁਹਾਨੂੰ ਆਪਣੀਆਂ ਬਾਹਵਾਂ ਜਾਂ ਲੱਤਾਂ ਦੇ ਕੰਬਨ ਦਾ ਅਹਿਸਾਸ ਹੋਇਆ ਹੋਵੇ ਜਿਸ ਨੂੰ ਤੁਸੀਂ ਰੋਕ ਨਾ ਸਕੇ ਹੋਵੋ?
2. ਕੀ ਕਦੇ ਤੁਸੀਂ ਡਿੱਗੇ ਹੋ ਜਿਸ ਦੇ ਉਪਰੰਤ ਰੰਗ ਪੀਲਾ ਪੈ ਗਿਆ ਹੋਵੇ?

ਮਰੀਜ ਨੂੰ ਮਿਰਗੀ ਹੈ ਪੱਕਾ ਕਰਨ ਲਈ ਦੋਵੇ ਪ੍ਰਸ਼ਨਾਂ 1 ਅਤੇ 2 ਦਾ ਉੱਤਰ ਹਾਂ ਹੋਣਾ ਚਾਹੀਦਾ ਹੈ।

3. ਕੀ ਤੁਸੀਂ ਕਦੇ ਬੇਹੋਸ਼ ਹੋਏ ਹੋ?
4. ਕੀ ਤੁਸੀਂ ਕਦੇ ਡਿੱਗੇ ਹੋ ਜਿਸ ਵਿੱਚ ਤੁਸੀਂ ਬੇਹੋਸ਼ ਹੋ ਗਏ ਹੋਵੋ?
5. ਕੀ ਤੁਸੀਂ ਕਦੇ ਡਿੱਗੇ ਹੋ ਜਿਸ ਵਿੱਚ ਤੁਹਾਡੀ ਜੀਭ ਕੱਟੀ ਗਈ ਹੋਵੇ?
6. ਕੀ ਤੁਸੀਂ ਕਦੇ ਡਿੱਗੇ ਹੋ ਜਿਸ ਨਾਲ ਤੁਹਾਡਾ ਪਿਸ਼ਾਬ ਨਿਕਲ ਗਿਆ ਹੋਵੇ?
7. ਕੀ ਤੁਹਾਡੇ ਕਦੇ ਬੜੇ ਹੀ ਘੱਟ ਸਮੇ ਲਈ ਹੱਥ ਪੈਰ ਜਾਂ ਫਿਰ ਤੁਹਾਡੇ ਮੂੰਹ ਦੀ ਕੰਬਪਣ (ਕੰਬਣਾ) ਹੋਈ ਹੈ?
8. ਕੀ ਕਦੇ ਅਜਿਹਾ ਮਹਿਸੂਸ ਹੋਇਆ ਹੈ ਕਿ ਤੁਹਾਨੂੰ ਆਲੇ ਦੁਆਲੇ ਦੀ ਸੁਰਤ ਨਾ ਰਹੀ ਹੋਵੇ ਅਤੇ ਕੁਝ ਅਜੀਬ ਬਦਬੂ ਆਈ ਹੋਵੇ?
9. ਕੀ ਤੁਹਾਨੂੰ ਕਦੇ ਕਿਸੇ ਨੇ ਦੱਸਿਆ ਹੈ ਕਿ ਤੁਹਾਨੂੰ ਮਿਰਗੀ ਹੈ ਜਾਂ ਮਿਰਗੀ ਦਾ ਦੌਰਾ ਪੈਂਦਾ ਹੈ?

ਜੇ 3 ਤੋਂ 9 ਕੋਈ ਵੀ ਪ੍ਰਸ਼ਨ ਦਾ ਉੱਤਰ ਹਾਂ ਹੈ ਤਾਂ ਮਰੀਜ ਨੂੰ ਮਿਰਗੀ ਹੈ।

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SECTION 2

Socio-demographic profile

Serial number **Date**

1	**Can subject answer for himself/ herself?**	1.Yes / 2.No
1a	**If no, who will?**	**Name** **Relation**
2	**Name**	**Mr./Ms./Mrs.**
3	**Age in completed years**	
4	**Gender**	1. Male 2. Female
5	**Address**	
6	**Mobile number**	
7	**Years of schooling**	
8	**Religion**	1. Hindu 2. Sikh 3. Muslim 4. Christian 5. If others specify..
9	**Caste**	1. SC 2. NSC
10	**Marital status**	1. Single 2. Widow 3. Widower 4. Divorce 5. Separated
11	**Living**	1. Alone 2. With spouse 3. With parents 4. With children 5. With other, specify
12	**Type of family**	1. Nuclear 2. Joint
13	**Working**	1. Working 2. Not working 3. Previously working 4. Household work
13a	**If working**	1. Agriculture 2. Business 3. Job 4. Labourer 5. Student 6. Professional 7. Other specify.....
13b	**If previously working**	1.Left voluntarily 2.Left due to stigma 3.Left against will 4.Left due to risks associated with job 5. Any other, specify.....
13c	**Income**	Rs. per month
14	**Ethnicity**	1.Punjabi 2.Migrant

The socio-economic status will be assessed by Modified Udai Pareek scale.

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Section 2A

Proforma for Socio-economic status for rural area

By Modified Udai Pareek scale

1. Caste
a) Schedule caste[1] b) Lower caste[2]
c) Artisan caste[3] d) Agriculture caste[4]
e) Prestige caste[5] f) Dominant caste[6]

2. Occupation (Head of family)
a) None[0] b) Labourer[1] c) Caste occupation[2]
d) Business[3] e) Independent profession[4]
f) Cultivation[5] g) Service[6]

3. Education (Head of family)
a) Illiterate[0] b) Can read only[1]
c) Can read and write[2] e) Primary[3] f) Middle[4]
g) High school[5] h) Graduate[6] i) And above[6]

4. Land
a) No land[0] b) <1 Acre[1] c) 1-5 Acre[2]
d) 5-10 Acre[3] e) 10-15 Acre[4] f) 15-20 Acre[5]
g) >20 Acre[6]

5. Social participation (Head of family)
a)None[0] b) Member of one organization[1]
c) Member of >1 organization[2]
d) Office holder in such organization[3]
e) Wider public leader[4]

6. Family members
a) Single[1] b) Size upto 5[2]
c) Joint family[2] d) Extended[3]
e) Any other distinctive feature[2]

7. House
a) No house[0] b) Hut[1] c) Kutcha house[2]
d) Mixed house[3] e) Pucca house[4] f) Mansion[5]

8. Farm power
a) No drought animal[1] b) 1-2 Drought animal[2]
c) 3-4 Drought animal [4]
d) 5-6 Drought animals[6]

9. Material possession
a) Bullock cart[0] b) Cycle[1] c) Radio[2]
d) Chairs[3] e) Mobile Phone[4] f) Television[5]
g) Refrigerator[6]

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Section 3. Seizure History

1. Duration since first seizure.....months
2. Whom did you contact at that time?
3. Duration since last seizure.....months
4. Whom did you contact at that time?
5. Current frequency of dominant seizure

   a) Daily b) Weekly c) Fortnightly d) Monthly

   e) Annually f) Sporadic g) Single h) Cluster
6. Description of prior seizure

   a) Daily b) Weekly c) Fortnightly d) Monthly

   e) Annually f) Sporadic g) Single h) Cluster
7. Was the treatment started? a) Yes b) No

   If no go to Section 6
8. When was the treatment started?
9. Type of anti-epileptic treatment? (Tick as many as possible).

   a) Allopathic b) Ayurvedic c) Homeopathic d) Faith Healer

   e) Others, please specify.....
10. How did you feel after starting treatment?

    a) Much better (b) Slightly better (c) Better (d) No improvement
11. Number of different medicine you are prescribed for epilepsy

    a) One (b) More than one
12. In a day, how many times do you have to take each medicine for epilepsy?

    (a) Once (b) Twice (c) More than twice
13. Can you name your medicine?

    (a)Yes (b) No

    If yes name.....
14. Are you currently on treatment with AEDs?

    (a) Yes (b) No (c) Don't know
15. If yes to question no 14,

    go to section 4

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16. If no to question no 14,

Did you stop medicine on advice of your doctor?

a) Yes b) No

17. If answer to question no 16 is yes,

then go to section 7

18. If answer to question no. 16 is no ,

Why did you stop the treatment?

i. You could not afford to buy medicine.
ii. You tried but could not find a place to buy medicine.
iii. You didn't know where you could buy medicine.
iv. You didn't want to buy it.
v. You were seizure free.
vi. Your seizures were not under control despite treatment.
vii. You were having side effects with medicine
    a. Specify side effect....
viii. You didn't have means of transport to go and get it
ix. You didn't have time to get it.
    a. Had to go to work.
    b. Had household work.
    c. Had other work. Specify.....
x. Your family is not supportive
xi. You got fed up of taking medicine
xii. Any other reason please specify.....

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Section 4 Treatment adherence

1. Do you forget to take seizure medication sometime?

   (a)Yes (b) No

2. Do you sometimes skip your medication?

   (a)Yes (b) No

   If no, go to Section 5

3. If answer to question no 2 is yes,

   Reason for skipping the anti-epileptic medicine:

   a. You could not afford to buy medicine.
   b. You tried but could not find a place to buy medicine.
   c. You didn't know where you could buy medicine.
   d. You didn't want to buy it.
   e. You were seizure free.
   f. Your seizures were not under control despite treatment.
   g. You were having side effects with medicine
      i. Specify side effect....
   h. You didn't have means of transport to go and get it
   i. You didn't have time to get it.
      i. Had to go to work.
      ii. Had household work.
      iii. Had other work. Specify.....
   j. Your family is not supportive
   k. You got fed up of taking medicine
   l. Holidays/ birthdays / other special occasion, please specify.....
   m. When you are going away from home.
   n. When you are around people who do not know that you have epilepsy.

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Section 5

Health care system availability and accessibility

1. From where do you take medication?
   a. Government
      i. Medical college ii. District Hospital iii. Sub district hospital
      iv. Community Health Centre v. Primary Health Centre
      vi. Subcentre
   b. Private
      i. Medical college ii. Clinic iii. Hospital
   c. Pharmacy
   d. Quack
   e. Faith healer
   f. Any other specify...

2. Is medicine always available? a) Yes b) No
3. If medicine is not always available at regular source
   a) Do you miss taking your medicine
   b) Buys or obtains from alternative source
4. Is doctor always available when you go to health facility?
   a) Yes
   b) No
5. Distance of health facility from your house?
6. Mode of transport
7. How much time does it take to travel to health facility from your home?
8. Does this distance to health facility keep you from refilling your medication?
   a) Yes
   b) No
9. Do you have difficulty in travelling to health facility?
   a) Yes
   b) No
10. If yes, elaborate
11. Who accompanies you?

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12. Were you counselled by health care personnel/ doctor on need of regular medication use and consequences of non adherence?	a) Yes b) No
13. Were you referred from one centre to other?	a) Yes b) No
14. If yes, did you follow up at the referred centre?	a) Yes b) No
15. If you did not follow up, then why?	
16. Does attitude of HCP towards your illness keep you from going to clinic?	a) Yes b) No
17. Are you satisfied with the quality of medical care at the health facility?	a) Yes b) No
18. For how much period drugs are dispensed at one time.	(a)<7 Days (b)7-15 Days (c)15-30 Days (d) >30 Days
19. For how long do you have to wait at hospital.	(a)<1 Hour (b)1-4 Hours (c) >4 Hours

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Section 6 Awareness about epilepsy

1 Have you ever heard of epilepsy before?

a) Yes
b) No

2 Is epilepsy a

a) Brain disorder
b) Mental illness
c) Hereditary
d) Contagious
e) Don't know

3 What do you think epilepsy is caused by?

a) Ancestors sin
b) God's curse
c) Spirit possession
d) Don't know
e) Karma
f) Any other reason specify.....

4 Do you believe that medicine (AED) prescribed now will control your epilepsy?

a) Yes
b) No

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x

Section 7 Medical and surgical history

1. Any co-morbid conditions
   a) Hypertension b) diabetes c) Coronary heart disease d) Stroke
   e) Any other please specify....
2. Concomitant medication
3. Any history of
   a. Fever
   b. Headache
   c. Focal Neurological deficit
      i. Weakness of one side
      ii. Numbness of one side
      iii. Vision loss in one side
   d. Febrile seizures in childhood
   e. Childhood Encephalopathy
   f. Neonatal hypoglycaemia
   g. Kernicterus
   h. Significant birth History
   i. Head Injury
   j. CNS Infections
   k. History of any brain surgery

Family history

Does any family member have a history of seizures or epilepsy? a)Yes b) No

If yes, who Relation

Consanguineous parents (parents married in a blood relation) a)Yes b)No

Any other significant history

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Social and Personal history

1. Number of hours of sleep a).....In day b).....At night
2. Sleeping area
   a) Sleeps alone
   b) Share a bedroom, but sleeps on separate beds
   c) Share a bed with someone
   d) Share a dwelling but have separate bedrooms
3. Diet a)Vegetarian b)Non vegetarian
4. Alcohol during treatment period a)Never b)Occasionally c)Weekly d)Daily
5. Smoking during treatment period a)Never b)Occasionally c)Weekly d)Daily
6. Any other substance abuse
7. Health insurance a)None b)Private c)Government d)Job benefit

Menstrual and obstetric history (for female subjects)

1. Age of Menarche Year
2. Last menstrual period ____/____/_____
3. Duration
4. Flow
5. Regularity

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6. Does seizure occur | Just before menses | Just after menses | No relation with menses

7. Number of Pregnancy

8. Number of Miscarriage

9. Number of live-birth

10. History of Birth defects in children a)Yes b)No

11 Any child with epilepsy a)Yes b)No

12 Remarks

Section 8 General Physical Examination

1. Weight..... ...kilogram

2. Height.....meter

3. BMI .....Kg/m^2

4. BP ...../..... mmHg

5. Pulse...../min

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INFORMED PATIENT CONSENT

Date: _____

I.....D/o, W/o, S/o..... .....am willing to participate in the study **"PREVALENCE OF EPILEPSY AND DETERMINANTS OF TREATMENT GAP IN PEOPLE WITH EPILEPSY IN RURAL LUDHIANA"** The procedure with its complications has been explained to me in local vernacular language. I have fully understood that no special tests and extra expenditure in any form, merely for the purpose of thesis is being carried out. I am free to opt out the study any time without assigning any reason.

....

Signature of the Witness Signature of the patient

Name:

Signature of Candidate **Signature of Supervisor**

ਮਰੀਜ਼ ਰਜ਼ਾਮੰਦੀ ਫਾਰਮ

ਮਿਤੀ_____

ਮੈ_____ਪਤਨੀ/ਪੁੱਤਰ/ਪੁੱਤਰੀ_____

ਵਾਸੀ_____

"PREVALENCE OF EPILEPSY AND DETERMINANTS OF TREATMENT GAP IN PEOPLE WITH EPILEPSY IN RURAL LUDHIANA" ਤੇ ਚਲ ਰਹੀ ਖੋਜ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਰਜ਼ਾਮੰਦ ਹਾਂ ।ਇਸ ਖੋਜ ਕੰਮ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਮੈ ਆਪਣੀ ਮਰਜ਼ੀ ਨਾਲ ਤਿਆਰ ਹਾਂ ।ਮੈ ਇਹ ਦਸਣਾ ਚਾਹੁੰਦਾ ਹਾਂ/ ਚਾਹੁੰਦੀ ਹਾਂ ਕੇ ਇਹ ਰਜ਼ਾਮੰਦੀ ਦੇਣ ਵਾਸਤੇ ਮੈਨੂ ਕਿਸੇ ਵੀ ਤਰਾਂ ਦਾ ਲੋਭ-ਲਾਲਚ ਨਹੀ ਦਿੱਤਾ ਗਿਆ ਅਤੇ ਨਾ ਹੀ ਕੋਈ ਦਬਾ ਪਾਇਆ ਗਿਆ ਹੈ। ਮੈਨੂ ਇਸ ਖੋਜ ਦਾ ਮਨੋਰਥ ਸਮਝਾ ਦਿੱਤਾ ਗਿਆ ਹੈ ਅਤੇ ਮੈਨੂ ਇਹ ਭਰੋਸਾ ਦਵਾਇਆ ਗਿਆ ਹੈ ਕੇ ਇਹ ਖੋਜ ਵਿਗਿਆਨ ਅਤੇ ਮਾਨਵਤਾ ਦੀ ਭਲਾਈ ਲਈ ਹੈ ।ਮੈਨੂ ਇਸ ਖੋਜ ਵਿਚ ਹੋਣ ਵਾਲੇ ਖਤਰੇ ਬਾਰੇ ਸਮਝਾ ਦਿੱਤਾ ਗਿਆ ਹੈ ਅਤੇ ਮੈਨੂ ਇਹ ਯਕੀਨ ਹੈ ਕੇ ਇਹ ਖਤਰਾ ਬਹੁਤ ਮਾਮੂਲੀ ਹੈ ।ਮੈਨੂ ਇਸ ਖੋਜ ਕੰਮ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਦਾ ਢੰਗ – ਤਰੀਕਾ ਸਮਝਾ ਦਿੱਤਾ ਗਿਆ ਹੈ।

ਮੈ ਇਸ ਖੋਜ ਕੰਮ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਬਾਰੇ ਆਪਣੀ ਰਜ਼ਾਮੰਦੀ ਕਿਸੇ ਵੀ ਸਮੇ ਵਾਪਸ ਲੈ ਸਕਦਾ ਹਾਂ/ ਸਕਦੀ ਹਾਂ ਅਤੇ ਮੇਰੀ ਰਜ਼ਾਮੰਦੀ ਵਾਪਸ ਲੈਣ ਦਾ ਮੇਰੇ ਇਲਾਜ ਤੇ ਕੋਈ ਅਸਰ ਨਹੀ ਹੋਵੇਗਾ।

_____ _____

ਗਵਾਹ ਦੇ ਹਸਤਾਖਰ ਮਰੀਜ਼ ਦੇ ਹਸਤਾਖਰ

ਮਿਤੀ _____ਮਿਤੀ

_____

ਪਤਾ _____ ਪਤਾ_____

_____

ਨਿਰੀਖਕ ਦੇ ਹਸਤਾਖਰ

_____

ਸਿਖਿਆਰਥੀ ਦੇ ਹਸਤਾਖਰ

मरीज अनुमति फार्म

तिथि _____

मैं _____ पत्नी/पुत्र/पुत्री _____

निवासी _____

इस शोधकार्य **"PREVALENCE OF EPILEPSY AND DETERMINANTS OF TREATMENT GAP IN PEOPLE WITH EPILEPSY IN RURAL LUDHIANA"** में भाग लेने के लिए सहमत हूँ। मैं इस शोधकार्य में भाग लेने के लिए अपनी स्वेच्छा से तैयार हूँ। मैं पुष्टि करता/करती हूँ की यह स्वीकृति देने के लिए मुझे कोई आर्थिक प्रलोभन नहीं दिया गया और न ही दबाव डाला गया है। मुझे इस शोधकार्य का उद्देश्य स्पष्ट कर दिया गया है और मुझे यह विश्वास है की यह विज्ञान और मानवता के लाभ के लिए है। मुझे इस शोधकार्य में होने वाले जोखिम के बारे में समझा दिया गया है और मेरी समझ में यह जोखिम बहुत मामुली है।

मैं इस शोधकार्य में भाग लेने के सम्बन्ध में किसी भी समय अपनी अस्वीकृति व्यक्त कर सकता/सकती हूँ और मेरे अस्वीकृति व्यक्त करने का मेरे इलाज पर कोई प्रभाव नहीं पड़ेगा।

_____ _____

गवाह के हस्ताक्षर रोगी के हस्ताक्षर/अंगूठे का निशान

नाम: नाम:

_____

अन्वेषक के हस्ताक्षर

_____

विद्यार्थी के हस्ताक्षर